claiming my future

A person with a mental disability today and tomorrow

90-00925/

LEGISLATIVE ASSEMBLY
ALBERTA

ROY BRASSARD, M.L.A.
OLDS-DIDSBURY CONSTITUENCY

Dear Reader,

When I was first assigned the task of chairing this committee, it is fair to state that I didn't know what I didn't know about the topic. In retrospect, this was an asset, because I had absolutely no preconceptions, and I tried very hard to maintain this position throughout the information gathering process. Therefore, I feel qualified to challenge you to regard the contents of this document with an open mind, since first impressions can sometimes present a very real barrier to acceptance.

When I began my journey of comprehension, I was introduced to countless individuals whose disabilities appeared to me almost insurmountable. I couldn't begin to recount them all, but let me tell you of one such person—a twenty-four year old, who could neither walk nor talk and whose only controllable movements were limited to nodding his head from left to right.

A rehabilitation practitioner was working with this individual and had designed a program on closed-circuit television, using a nod to the right to mean the affirmative while a nod to the left meant the negative. Each such nod activated a lever attached to the wheelchair. Some of the programs were entertaining, but others were purely functional—breakfast menus, personal comforts, etc. I suddenly realized that for the first time in his life a measure of personal control had been introduced into a life that had hitherto been completely and totally dominated by others. And the word recipient had been changed to participant.

No one could tell me where they thought this program would eventually lead, but the possibilities seemed to me to be limitless. And I realized that we cannot attain to a vision, we must live in the inspiration of it until it accomplishes itself. The question then becomes, how do we attain this vision?

The Review Committee recognizes that services have always been developed with dedication, and they have been developed according to how people with disabilities were seen at the time. As a result, the Review Committee listened to many citizens but felt compelled to base this report on the views of those citizens with mental disabilities.

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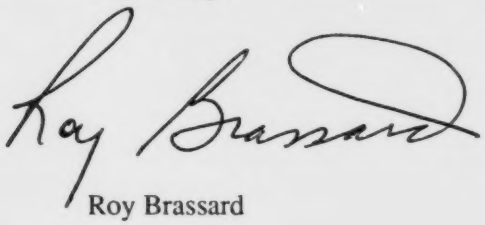
Claiming My Future, then, calls for us all to re-evaluate how we think and act to make sure that citizens with disabilities enjoy their rights. We believe society must restructure its services, its organizations' roles and responsibilities, and its resource allocations to promote the rights of all citizens with mental disabilities. We invite you to embrace this challenge for a better future for us all.

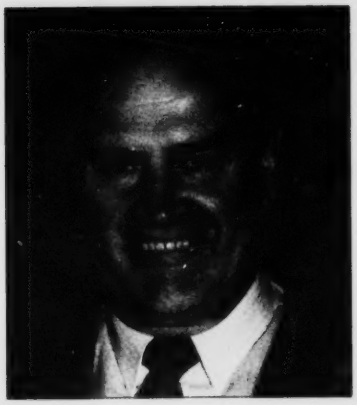
I have seen those who have been segregated because of their disabilities. I also have seen those who have been integrated into the community. And I tell you this. Integration not only enriches their lives, but ours. Our investment is not only in their future, but in ours. In that future, we will no longer speak of the disabled but of people.

Yours truly,



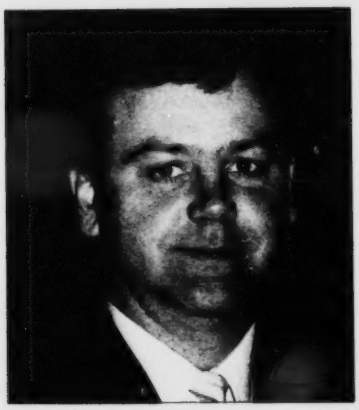
Roy Brassard

The Brassard Committee

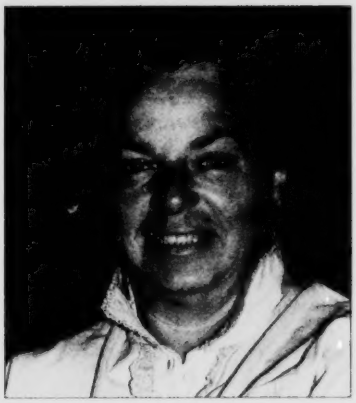


Roy Brassard was born and raised in Thunder Bay, Ontario, and took business administration courses in Winnipeg. He has been in the service operations of the automotive industry most of his adult life, culminating in a General Motors dealership in Didsbury, Alberta. Roy Brassard has always been involved in community issues and was elected to the Legislature in May 1986. He is married to Sheila Brassard and has four children, Scott, Cal, Terryl, and Alison.

Rose Marie Nicas was born in Edmonton, Alberta, and received a B.Sc. in Pharmacy at the University of Alberta. She helped set up the Gingerbread Kindergarden in Lethbridge and worked on a volunteer basis with children with mental disabilities and autism at an elementary school in Lethbridge. Rose Marie Nicas has served for five years on the Board of Governors of Grant MacEwan Community College and is employed at the University of Alberta Student Health Services as a pharmacist. She is married to Dr. James A. Nicas and has two daughters.



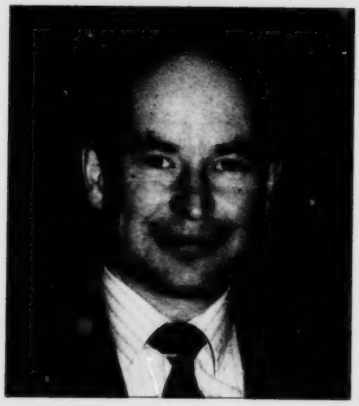
Don Schultz owns and operates a farm machinery dealership in Barrhead. He has been a member of the town council for the past six years and is a past member of the Lions and Kinsmen clubs. His daughter Kyley-Jo has physical and mental disabilities. As a result, his wife Barb is a teacher's aid in the local school for children with mental and physical disabilities, and he has been and still is involved in Special Olympics locally and provincially. Don Schultz has three children, Terris, Kyley-Jo, and Jordan.



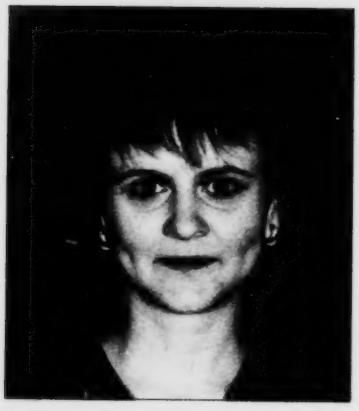
Nomi Whalen has been a junior and senior high school teacher in the Calgary Public School System. She was a member of Alberta's first Human Rights Commission and an alderman for the City of Calgary. She also has served as a policy advisor to the ministers of Alberta Transportation and Alberta Hospitals and was a newspaper columnist. She is now a family counsellor and writer living in Calgary.

Chris Whittaker is the general manager of Childspace Manufacturing Limited, a business established with the twin aims of providing viable employment to people with mental disabilities and of operating as a business within the business community, receiving no grants or funding other than those available to any business in Alberta. He is the past chairman of Horizon School in Olds, a school for children with developmental disabilities. Chris Whittaker is married to Jean Whittaker and has three sons, Peter, Andrew, and John, the eldest of whom is sixteen years old and was born with Down's syndrome.

The Brassard Committee Secretariat



Allan Douglas entered the field of vocational rehabilitation in 1972, when he began to help people with disabilities prepare for and obtain employment. Since that time, he has developed new services and worked within government to support the development of community-based agencies. Most recently, he was appointed as the provincial co-chair of a federal/ provincial/territorial review of cost-sharing mechanisms to support services to people with mental disabilities.



Helen Stacey graduated from Brandon University in 1978 and began working with people with mental and physical disabilities. She has worked with people in an institutional setting in Manitoba and in group homes and a vocational centre in Alberta, where she has lived since 1980. Most recently, she has helped plan individual service options.

Many Albertans are placing a tremendous amount of hope and trust in the results of the work of the Brassard Committee. It is in the spirit of this hope and trust that we ask you, the reader, to take the time to read this document in its entirety.

We speak for some Albertans who cannot speak for themselves. We believe it is fair and, indeed, essential, that the totality of the effort during one year of reading, listening, discussing, and writing be experienced by the reader.

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Acknowledgements

When we began the Brassard Review one year ago, we could not have imagined how much we were about to learn about people with mental disabilities, the service systems, the issues and challenges, or the dedication and commitment of so many people throughout this province.

Our initial questionnaire started us on a journey of personal knowledge as we began to learn about the wide range of philosophical beliefs about the future and the issues regarding services in this province. We owe a great deal to the people who submitted information as a result of the questionnaire. We wish to thank each and every one of them for the time and energy they put into their submissions and for their willingness to share personal experiences, professional knowledge, and, in many instances, the emotional and highly personal experiences of families who have lived through many changes in service delivery and philosophy.

It was through these submissions that we began to understand and appreciate the complexity of the task that faced us. The submissions to the Review did increase our knowledge immensely and enabled us to prepare our information base for distribution to interested people before we held public forums.

We believe that our real knowledge and personal growth experience began when we started our travels and public forums throughout Alberta. While we felt informed about many things from our questionnaire, we had not yet begun to experience the emotion, commitment, dedication, or hands-on experience that developed as we met people with mental disabilities, advocates, families, staff, and agency personnel in our travels.

The profound impact we felt as we visited and talked with people with mental disabilities in institutional services, group homes and workshops, schools, family settings, and individual services gave us the knowledge of how philosophies and service decisions truly have an impact on the lives of people. We would like to

thank the people who shared their experiences with us and opened up their homes, agencies, and worksites to help us better understand the complexity, challenges, and issues of this Review.

We would also like to thank the residents and staff of Youngstown, Michener Centre, Bow Island, Fort MacLeod, Eric Cormack Centre, and Rosecrest Home for the tours of these facilities and for their willingness to share their experiences, hopes, and desires with us.

We also wish to thank the many people who attended the sixteen public forums that were held in the province. We were most grateful that people willingly shared their stories, triumphs, frustrations, and challenges, and we heard the heartfelt requests to address concerns and make appropriate recommendations to the Minister. We were struck by the fact that regardless of differences in philosophy each person wanted to do the right thing to improve the lives of people with mental disabilities and were committed to this task.

The hospitality we experienced in each location of our public forums was greatly appreciated, as we felt at home wherever we went.

We also wish to say a special thank you to families who shared their feelings and experiences with us in a variety of ways. We owe families much for their perseverence and their honesty in sharing personal information, and their struggles in such an honest and open fashion enabled us, first hand, to learn of their joys and sorrows.

When the Review first began, we anticipated that to provide an overview of all services to people with a disability our approach would be a simple matter of designing a spreadsheet of services available in the province. It quickly became obvious that a review of services would have to be far more detailed than that and would have to include an examination of values, issues, services, and a myriad of opinions regarding where services should be moving in the future. The spreadsheet idea gave us an excellent starting point to determine what services were available and provided us with the base from which we could begin to ask more detailed questions and seek opinions about the future of services.

We would like to say a personal thank you to Ute Davis, Glenna Bell, Jacqueline Moore, and Susan Zukiwsky of the Social Care Facility Review Committee (SCFRC), who provided us with the baseline information about vocational training in Alberta.

The SCFRC visited a total of fifty-nine vocational services in the province and provided us with information about the types of services available, the people who were being served, the budgets allocated, and the goals of vocational training in Alberta. From this information, we discovered we have services ranging from large vocational training services involved in contract work to individual employment options in the community. We also saw that many centres are beginning a transformation from facility-based services to employment in the community, and there appeared to be a growing trend toward this objective. The information provided by the SCFRC has been used throughout this document, particularly in the section on employment and training, and has helped us formulate our recommendations about the future of these services.

We also wish to thank the many people from British Columbia, Ontario, and the United States who met with us and helped us gain information and insight into the issues and the future of services for people with mental disabilities. We were most appreciative of the willingness to share experiences both positive and negative that helped us learn from the experiences of others.

We also thank Kathleen Keohane, Christine McMullen, Gail Roberson, Wayne Wright, Joan Charbonneau, Terry Downton, and Mary Kay Russell, members of the Consultation Committee, who helped us refine and expand the first document we prepared – our information base document – and the many people who met with us to help clarify issues and heighten our awareness and understanding.

We thank the consultants and students who assisted us in the preparation of the information base document. Their analysis of the tremendous volume of paper work provided us with the ability to prepare our initial information.

We must also thank Adele Johnson for her organizational skills and the ability to word process a tremendous amount of information for the Review. Emily Tislak is also thanked for completing the word-processing task in the final month of the Review.

We thank Sylvia Vance for her ability to take all of the information, our emotion, and our desires and use her creativity and talents to pull it all together to prepare this final document.

Our largest debt of thanks goes to the people with a mental disability who represented themselves or were assisted by others to tell us of their hopes and dreams for the future. It is from these Albertans that we have learned the most and about whom we have directed our recommendations for the future.

We have listened to many people's opinions about the future direction of services for people with mental disabilities, and we would like to thank those whose words appear in this document. But we believe that the most important voice, and the one we listened to in drawing our conclusions, belongs to those people whose lives are ultimately affected by the service directions and philosophy contained in this document.

We hope that we have been able to lay a foundation for a better future for people with a mental disability, and it is to people with a mental disability that we dedicate this document. We offer it to you, the reader, as a compilation of our ideas about the right direction for the future. We believe that this direction will truly improve the lives of each person in Alberta with a mental disability as they become full and equal citizens of this province.

Introduction

We are living in an era of real change for people with mental disabilities. People with mental disabilities are in the community in ever-increasing numbers and are struggling to involve themselves in work and play in the same way as we all do. This struggle is not without its difficulties. There are easily enough homes and services within the communities to fully support the people who wish to live there. There could be enough employment or recreation opportunities. There could be enough financial support or education programs. Homes and services, employment or recreation, financial support or education programs are not the real barriers to integration. The real barrier is that there is not enough acceptance by other people already within the community or in the workplace. This will come, and must.

To this end, the Brassard Report speaks to a time when all people will be accepted within the community, whatever their abilities or disabilities, whatever their advantages or handicaps. We look to a time when people with mental disabilities will be fully integrated into the community, about the year 2010. It will be a time of a more tolerant and, we hope, kinder society.

At the same time, this report speaks to the past and the present. We attempt to understand where we are by looking at past decisions without judging those decisions. We look at the present as a basis for the future and as a measuring stick of how far we must go to achieve the end of full integration. It is, in some areas, a long journey. But the journey is already begun. People with mental disabilities are learning how to live as full members of society, with the full rights and responsibilities that we imply. By this report, we hope to encourage and support them in their journey.

The Brassard Report draws extensively on the submissions the Review Committee received, the information made available at public forums, and our many discussions with individuals who support people with disabilities. Most importantly, the Committee drew from what people with mental disabilities said about their wishes and desires for the future. We have included the voices of these people as a reminder of what we heard.

In the report, we have looked at the support and services now available to people with mental disabilities and those that must be available in the future. We have included the key areas, with the realization that we will have missed areas that may be important to some people. We hope that those people will find the answers they need in the general overview of the report. While we focussed our attention on those with mental disabilities, we recognize that many of the issues we address and the recommendations in the report can be applied to people with other disabilities. It must be remembered, as well, the many people with mental disabilities have other disabilities. In each of the key areas, we have done what we can to look at the future in as concrete a way as possible. We realize, of course, that we cannot see the future and that the future depends on what happens now.

The report is divided into sections that describe specific services or systems. Within each section, we look at the past and present, then at the future. At the end of each section, we make recommendations to government, specific government departments, specific services, or to society at large. The language in some sections may seem dry. The language we use about caring for people is sometimes clinical. But we would like to remind the reader that these words are about people and about those people's lives. These words are about people's fears, hopes, aspirations, and dreams. These words are about people's futures. **They must be heard.**

Out of the Past: The First Step

Most people in society thought people who were mentally disabled were people who could not do things. We thought of them as patients who required protection, care, and treatment. We thought that the best way to take care of them was to give them services that were specialized in nature, located in specialized places, and staffed by specialized personnel. We believed it was best to bring all people with disabilities together and separate them from the mainstream of society. Institutional services were fairly fixed at first, but then they evolved from a **medical model**, where people were being taken care of, **to a developmental model**, where people began to learn to take care of themselves. This change occurred when we learned that **people with mental disabilities were capable** of much more than we had originally thought.

Introduction to the Community: The 1970s

Because of a growing body of knowledge about people's capabilities and the beginnings of normalization, community-based services started developing in the 1970s. We started to look at a person with a mental disability as a client with particular needs and not as a patient who was sick. Services were still specialized, as was funding, but we believed that grouping people based on common needs was the best service model. The **group homes** and **workshops** that were developed gave an opportunity to people with mental disabilities to demonstrate that they could live in the community. Society at large learned that **institutions were not the only alternative**. People learned that you did not have to be afraid or ashamed of people with mental disabilities, as they became more visible in shopping centres, in churches and on playgrounds.

Changes in the 1980s

In the 1980s, we began to ask questions about whether or not we should group people with disabilities together as if they all had the same needs. As one answer to these questions, group homes and workshops started giving more individual attention to the people living and working there. As another answer, many other support services were developed. Those support services became the responsibility of Alberta Family and Social Services. Community and support services began to grow and the size of **institutional services began to decrease** as more and more people with disabilities lived in their communities.

> *"The rural community in which we are living has surrounded us with their care and compassion and are totally involved in helping our son grow and develop."*

In the 1980s, there was another change in how we saw people with mental disabilities. In the seventies, there had been the change of seeing people with mental disabilities as patients to seeing them as clients. In the late eighties, we changed our view from seeing them as **clients to** seeing them as **citizens**. Through self-advocacy, people with mental disabilities taught us that they wished to be seen as **people first**. Now, instead of thinking of what they can't do, we think of what they can do. We have begun to enter a time of **thinking of ability**,

and this has led directly to the call for individualized, personalized services based on a person's strengths and abilities. People with mental disabilities have demanded to live life like the rest of us, work in the community, live in the community, and take part in community life. At the same time, it is not enough to live in the community without also recognizing the right to take part in community life. Our changed perception has resulted in more attention being paid to basic **civil and human rights**, equality, community presence, and the acceptance of people with mental disabilities as **people first**.

The Future

When we look at the year 2010, then, we see a time when people with mental disabilities will be using the same services that are available to everyone in our society. These services will be based on what a person wants and wishes for, and funds for these services will be based on each individual's needs and will give them the power to meet these needs. The society of 2010 will be one that is tolerant and accepting and will include people with mental disabilities in everyday community life.

The Committee believes that the way we view people with mental disabilities in the future will be as individuals who have every right to be full and participating members of society, who have the same rights, entitlements, responsibilities, expectations, and opportunities as everyone else. This means that the way we view people with mental disabilities now and until that time will have to change. No longer should people with mental disabilities have to fight for a place in society. People with mental disabilites must be seen as citizens of society, no different from the rest of us.

"Philosophically, we should be governed by one word—choice."

To help change how we look at people with mental disabilities, the Review Committee has adopted the World Health Organization's system of defining disabilities. These definitions show us that the real handicap is when a person cannot get work, take part in recreational activities, or receive an education.

The World Health Organization classification system describes impairments, disabilities, and handicaps. It describes a disability as something physical that does not allow a person to carry out an activity, in a manner, or within limits,

considered normal for the average human being. More importantly, it describes a **handicap** as something **imposed by society** which does not allow a person with a disability to fulfil social roles. This is an important distinction. A disability cannot be changed by society at large. A handicap can.

The Review Committee thinks that society can change and can decrease the things that make people handicapped. Society can do that by realizing that people with disabilities are contributing members of society. Society can do that by making sure that individuals are given every chance to be in our communities and by supporting and helping people become full members of our society. This change will take time, but the Review Committee believes that the only way to make sure that each person has a life of good quality is to begin to think about, adapt, and organize services and support so that those services and support help people direct their own lives.

From Client to Citizen

As citizens of Alberta, we live as if we have a right to make our own decisions, a right to direct our own lives, and a right to be contributing members of society. Yet, we have not begun to make sure that people with mental disabilities are aware of and can exercise these same rights. For each person to be a true citizen and be integrated in our communities, all people in society must accept and respond to them. The Canadian Charter of Rights and Freedoms guarantees the rights of all of us, including people with mental disabilities. Now, those **people are claiming their fundamental rights and responsibilities.**

In the future, the Review Committee believes that we will not think so much about whether or not people with mental disabilities can be seen as citizens. Instead, we will have to think about how to make sure that they can practise their recognized citizenship. The Committee's view of the future focusses on regaining civil rights and on the recognition of people with mental disabilities as individuals who have basic human rights that are no different than the rest of society.

> *"The community must bring people with disabilities into integrated systems designed for them. After all, who is disabled—society or those it labels?"*

We are pleased that Alberta's Individual Rights Protection Act will be amended to include people with mental disabilities. Under the Act, people with mental disabilities will be guaranteed protection from discrimination in employment, accommodation, services customarily available to the public, and the ability to become members of a trade union. At the same time, the rights guaranteed under the Canadian Charter of Rights and Freedoms will set the stage for the guarantee of such rights as:

— freedom of conscience and religion
— freedom of thought, belief, opinion, and expression
— freedom of association
— the right to vote in elections
— the right to life, liberty, and security
— the right to not be arbitrarily detained or imprisoned
— the right to not be subjected to any cruel or unusual treatment or punishment
— equality before and under the law
— equal protection and equal benefit of the law

These rights will apply without discrimination against race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

The guarantee of legislated rights will begin to do much to help individuals assume their places in society. In order to recognize and fully accept citizenship, however, it is most important that attention also be given to the basic human rights that each of us expects as a member of society.

The Review Committee believes the future will be one characterized by **respect** for each person's dignity and worth, regardless of the degree of disability. To respect people's dignity, we must begin to focus our values on the basic things that make up a quality lifestyle for each one of us. Each of us has come to expect that we will be **informed citizens**, that we will be allowed to **make decisions in our lives**, that we will be able to **take risks** as we see appropriate, that we will have a basic control of our own lives, that we will be **valued members** of society, and that we will be given the opportunity **to contribute** to life in society.

All of us have basic needs that must be met. We have the need to **live under a decent standard of living.** Each of us needs to **be loved and to love** in return. Each of us needs to be **understood** and **accepted** for who we are, to grow and develop morally and spiritually, **to live and work** where our self- esteem can be enhanced, **to form friendships and relationships** that are life long, to be given

opportunities to **gain skills**, to be **recognized as the unique individual** that each one of us is, and to **demonstrate our strengths and abilities** and **receive support of our needs and our deficits**.

Each one of us should have the right to lead a **satisfying and productive life** to the best of our ability—lives that provide us with challenges and do not make assumptions that we will not be able to do what we set out to do. Each of us requires **a sense of belonging**. We need to belong to our families, our friends, our neighbourhoods, our schools, our places of employment, our recreational centres, and our church groups.

Each one of us also expects to be able to **make choices** in our lives, to **make changes** in our living or working environments, and to be supported in making these changes. We all depend on one another, and individuals with mental disabilities are no different. All of us learn from society and from the people we meet, and we **give back the things we have learned and help other people**. Each of us needs to learn what we are entitled to and what our responsibilities are. We need to be given an opportunity to **practise** these **rights** and **responsibilities**. All of us need opportunities to develop valued skills and to be in situations that enhance our image and do not exaggerate our differences.

In the future, each individual will become a valued participant in our communities. To realize human rights, it is critical that individuals with mental disabilities have the maximum opportunity for community presence and integration. All of us expect to have our human needs met in normal ways by our society's systems and support, and people with mental disabilities should expect no less.

The Review Committee sees a future that is characterized by a welcoming attitude of all citizens, whatever their abilities or disabilities. That future society would support individuals in their growth and participation in society.

Services and Support

> *"Every individual has the right to live a life of dignity—to feel accepted by others, to be treated with respect, and to have the opportunity to take risks. Every individual has the right to live in an environment that allows these needs to be met."*

With a changing value base and a changing perception of people with mental disabilities, it logically follows that our methods of providing support and services to people must also be adjusted. The full citizenship rights and responsibilities of each person must be recognized. People with mental disabilities must have a full community presence and integration and must be provided with a full opportunity to excercise self-determination and control over their lives. The emphasis must be on the person and his or her abilities, rather than on his or her disabilities, with the recognition that each person is a valued and contributing member of the community.

The Review Committee recognizes that the degree of support needed in order to exercise full citizenship will vary from individual to individual. Whatever the degree of ability or disability, individuals must be supported in their attempts to direct their lives. Families, guardians, service providers, and others must make sure that basic rights are met. People must be seen as people.

> *"We, as a society, must stand up and say that if the services are needed we will provide and pay for them."*

In the future, support and services must be developed from an individual's needs and abilities. The individual, her or his personal support network and family, the community, and providers of services must all have a role in planning. Services must be flexible and adaptable to the changing needs of the person. Service planning based on the individual must be the norm in the future. Planning must be done by and with the individual rather than services and support being set up to satisfy what is seen as the common needs of people.

Support and services must no longer be focussed exclusively on rehabilitation programs. We have learned that people's needs, whatever their ability or disability, are the same. Therefore, support and services must be about meeting needs in such areas as accommodation, employment, education, transportation, and training from the systems already in place. Meeting needs will not be focussed on programs but will seek to help individuals to participate in and contribute to community life. Rather than community living, the future will be about living in the community.

> *"People with mental disabilities should be taken from where they are and worked with to help them develop to the highest potential and where they want to be."*

With a changing focus on where services are provided and how they are provided, our approach to support for people also must be different. The future will show that people with mental disabilities can develop skills, learn appropriate behaviour, and develop relationships with the help of ordinary people. Developing and sustaining relationships will be valued, as will the development of a support network. Social and emotional support will be seen as being just as important as where a person receives services. Services and support must be designed and developed around the person and must continue for as long as the person chooses. Because services and support will be developed around the needs and abilities of the person, they will be flexible. We will have the ability to create services when a need is not being met.

In the future, services and support must do everything to help maintain ties that a person develops with family, neighbours, community, classmates, and fellow employees. The individual must be fully informed about his or her choices, with the recognition that only the individual can make choices about his or her life. The individual must be supported in the choices made.

In the future, services and support must be accountable to the individual. The ultimate monitoring and evaluation of services and support must include the individual and the important people in her or his life. It must focus on the quality of life and on enabling people with mental disabilities to engage in that life. We have long since surpassed a value base that considers people with mental disabilities as dependent and passive receivers of services. We have learned that people with mental disabilities are capable and are entitled to live a life of mutual reliance, to use their talents to earn the respect of others, and to become meaningful and contributing members of community life.

The Review Committee has articulated many of its values and principles to characterize the future. We have chosen the theme of citizenship as the way of the future. We believe that people with disabilities must be accepted in our society and that society must begin to organize and adapt systems to include people with disabilities. The future should be one in which people will no longer be handicapped by the society in which they live.

> *"People with mental disabilities should expect the same rights and every reasonable opportunity that all citizens have. All handicapped people have the basic right to live and work in the community."*

As a result of this vision of the future, the Review Committee recognizes the following philisophical base: As citizens of this province, all Albertans must have the same rights and responsibilities, all citizens have the right of self-determination, and this right must not be abrogated.

The realization of full citizenship for each person and her or his right to full integration **will require an acceptance of and a response from many services that currently do not provide services to people with mental disabilities**. We are confident that the people of Alberta and those involved in the services now available will rise to the challenge of meeting the goal of a quality lifestyle for each person in the province of Alberta.

We have learned through the course of this review that in many ways Alberta is on the leading edge of services delivery to people with mental disabilities. We know that the combined efforts of those who support individuals with mental disabilities, our extensive network of community service providers, a willingness in government, and people with mental disabilities will create a future that truly realizes the inclusion of all citizens.

There is an extensive body of knowledge in the communities of Alberta that will contribute to opening the doors of acceptance and inclusion of people with mental disabilities in all aspects of society. Acceptance will take time, but we are confident that the province will respond to the challenges that lie ahead.

> *"Communities can demonstrate they believe in the dignity and worth of all citizens by ensuring that everyone has equal opportunities."*

During the course of our review, we were presented with an essay written by a Grade 10 student. It seemed to summarize our hopes about a different future for people with mental disabilities. The writer reflects on what happens when society segregates people with mental disabilities but also gives us a blueprint for accepting people in the future. We believe the message of this young writer is one of a future of tolerance, acceptance, membership in society, and a focus on a bright future that does not separate people with disabilities from people who are less disabled. We share this essay with you as a means of reflecting on our past but, more importantly, as a key to the future.

Friends by Lisa Grekul

I remember Robbie. He lived down the street from my house on the corner. I used to see him when I walked to school, and sometimes I wondered where he went every morning. Robbie did not go on a regular bus with the regular kids. Mom said he was special, so he had to go to a special school. The other kids used to laugh at Robbie because he walked funny, and I told them it was because he was special. They said he talked like a baby and what was so special about that, but I kind of figured he really was special, like maybe God gave us Robbie for a reason.

Once I went to Robbie's house to play. His grandmother ran out of the house and shood me away. All I wanted to do was talk to him, but she didn't understand. Mom says she was afraid I'd tease him like the other kids. I wouldn't. I won't ever forget the sad look on his little face smeared with dirt from playing alone in the yard. I wanted to hold his hand and run away from the world because God gave him to us and we should have taken care of him.

But we didn't. I grew up and out of grade school into high school. We knew it all, but we knew nothing. Of all the lessons we'd learned, all the books we'd read, what became of compassion? What happened to love and acceptance for all mankind? Why did we cringe and look the other way when the Robbies of our world smiled and waved? It took me years to finally realize why we have been given Robbie, but it was too late for me and too late for Robbie. He had so much to teach—humility, the beauty and fragility of the human race, love. God gave us Robbie to brighten the darkness we live in, but it never shone.

And so now I look back, wishing that we hadn't lived in two different worlds, Robbie and I. He was shuffled from school to school. I was angry. Angry because I hadn't learned the responsibility to help him when he needed help and to stand by and applaud when he achieved. There was so much for him to become and to contribute. Society needed him, not to exploit but to educate. For, in the process of showing society all that he could do, we could all learn to love and accept Robbie, but society didn't give Robbie the chance he needed . . . we needed.

Don't give up on the Robbie in your neighbourhood. Robbie is handicapped, but he is a person. I remember Robbie, he lived down the street from my house on the corner. I used to see him when I walked to school and sometimes I wondered where he went every morning. He should have gone to school with me with the regular kids. We would have grown into different people, and Robbie would have been my friend. That's all God ever wanted us to be, friends.

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Many individuals at public forums told us that **we are all a product of a society that has accepted the segregation** of people with mental disabilities. They believe that **future generations will no longer accept that people with mental disabilities should be separated from the mainstream** of society. They believe that the way to ensure that people take their rightful place in society is to begin to take steps today that completely integrate people with mental disabilities into all of our lives.

We begin our review with the family. It is the families of people with mental disabilities that have been at the forefront of change. Those families need and will continue to need support for change. And it is in the family that we will all learn to accept all people. Acceptance within the family means that future generations will grow up accepting a person with differing abilitities as just one more person who stands by them in school situations, at work, in their neighbourhood, and on the skating rink. The children of today will grow into adults who will be accepting, tolerant, non-discriminatory, and caring of all people, whatever their abilities.

Family Support and Assistance

"As society accepts more responsibility for meeting the needs of people with disabilities, it cannot ignore the primary role and responsibility of the family."

Family life is important to all of us as a place to **find love** and **security, comfort** and **continuity**. It is within a family that all of us **learn to grow** emotionally and socially. Living in a family teaches us how to **interact with other people, form and maintain relationships**, and how to **interact and contribute to our neighbourhood and our community**.

In the early years of service development in Alberta, there was little available support for families to keep their children with mental disabilities at home. In many instances, **children were separated from their families so that they could receive services**. These **children lost a critical bond** with their families, **lost their heritage and culture**, and had to rely on specialized personnel to meet their needs. While those caregivers did an admirable job of providing the care and treatment considered necessary for children with mental disabilities, it was not possible for them to duplicate the family.

In listening to families, we learned that many families chose not to have their children separated from them. They lived through many years of having to struggle for services and support. During the time when all services to individuals with mental disabilities were congregated and segregated, support and services to families who chose to keep their children at home were almost non-existent.

During the 1970s, services and support began to be developed in response to parental advocacy. Programs such as Handicapped Children Services and Alberta Aids to Daily Living were developed to meet the financial and equipment needs of families. Relief options, parental support groups, and advocacy groups grew in the communities as families attempted to support one another and have a forum through which they could articulate their needs to people in government and in agencies.

We were impressed with the commitment we heard from families and their capabilities and willingness to care for their children. We were disheartened to learn that **families still feel that they must fight for every service they receive**. In many instances, they **feel that they must beg** for the available services. In a future that sees children growing up in their families, every support and service must be provided to enhance family capability. The very services designed to assist families should not create barriers or handicaps for the family or the children. Services must be available when they are required and should continue for as long as they are needed. Various stages of a child's growth need different kinds of support. It is critical that support and services be personalized and be made for the individual to support and serve that growth.

Parents told us that one of the greatest **unmet needs** is that of **information** and **awareness**. Upon birth or diagnosis of a child with a mental disability, families want to understand their child's disability, what her or his capabilities and needs will be, what support and services are available, and what the future holds for them as well as their child. Without this information, people feel isolated and the family is put under increased stress.

Families are often told of their children's limitations and what they will not be able to do. They **seldom receive information**, however, **on the possibilities and capabilities of their children**. The first contact the parents have after the birth of their child often sets the stage for the kinds of services and support the parents choose and the responses they have. They may be given the impression that the only choice they have is to put the child in an institution. **When parents are told to** institutionalize the child or in some way **remove the child from the family, they are left with the impression that they are not capable of caring for their own child**. Families struggle long and hard with this advice, even years after they received it. If they decide not to take the advice, they are made to feel that they may be doing a disservice to their children. Thus begins a long struggle and fight to try and get the right services within their community.

> *"As a parent of a mentally disabled child, I also need a support network. I need help from my family and professionals to give me the time to develop so that I can grow and devote time to my other children."*

Families require **emotional support**, and many have said that other families are the best source of information and support. Families need to know that they are

not alone in their feelings and need assistance to work through a variety of concerns. To support their children in the family unit, **families need access to services** such as relief options, counselling, education, early intervention, infant stimulation, behavioural specialists, homemakers, home renovations, and a financial commitment.

"It took me four years to find Handicapped Children's Services."

Family members told us that there **is a lack of information and accessibility to the services and programs that do exist**. Without the necessary information about the possibilities and the services available, families are **unable to make informed decisions** about choices for their children. Families often indicated to us that they **felt lucky** if they found someone who could provide information to them or they heard it second-hand from others who had been able to secure a specific service. They thought the information should be readily available and that finding out about services and support should not have to be a matter of luck or a scavenger hunt. They **need a central location** to go to to find out all of the necessary information, rather than having to go to several different locations, make many phone calls, and, in general, run around and hunt for the information they require.

When families finally get the information they need, they find another barrier to their access to services. They discover that **services have long waiting lists, severe budget restraints, stringent criteria for eligibility**, and many hoops to jump through before service is available. In many instances, families told us that by the time their child's name rose to the top of the waiting list the service was no longer required. **Families** are completely frustrated by this process, since they **recognize that the earlier the child receives support and services the better off the child will be. They are unable to have the service when it is required and when it would do the most good.**

Families express a great deal of **concern about the fragmentation of services**. They must run between departments to secure services and support for their children. There is **no co-ordinated effort among the various service providers**. Without a co-ordinated effort, families feel that departments are constantly **passing the buck** or moving them over to someone else rather than providing services. There seems to be a **lack of information about the mandates** of various programs and services . This lack of information leaves families **unsure of their right to ask for a service** and of their **recourse if no service is**

forthcoming. To this end, there needs to be an appeal mechanism that functions across the various available support and services. Families expressed a lack of contact with people who make the decisions, and, often, service denials are not accompanied by an explanation of why services were denied or why families were ineligible for services. At the same time, they feel that they can provide solutions to the problems in the service system but that **if they complain they may lose the services and support they do have**.

"Available services seem to be a big secret."

Families often feel devalued by the very services and support that are supposed to be helping them. They want to be treated with respect and do not like being put in the position of constantly having to fight for everything they get. They would like alternatives to this fighting model, but they have come to rely on it as the only method that works.

Families indicated that there is a **lack of essential services** such as **speech therapy or physical therapy and occupational therapy**. Where these services do exist, there are not enough of them to meet needs. Families also want training in areas such as behaviour and medical intervention, planning for the long-term needs of their children, philosophical direction, and rehabilitation techniques.

When we look at rural areas, it is apparent that many of the services that do exist for families in an urban centre are non-existent in rural and northern communities. Families, then, have to move from their home community, travel great distances, or send their children away to try and secure the services they need. They are again at great risk of being separated from their children.

Families have told us that their future view of the world is one in which their children are fully integrated across all of society. While they believe this, their biggest struggle seems to be simply getting people to accept that their children have a right to integrated daycare, integrated education, integrated recreational activities, and, in general, to be part of the community in which they live.

"Relief services need to be available so that families don't burn out."

Relief services would **appear to be the largest unmet** need of families today. Families readily accept the responsibility for raising their children, but they indicate that there are times when they need relief from primary care. Parents told us the available relief services are both **insufficient in numbers and do not truly meet their needs**. They must plan months in advance for relief services, and there is little flexibility for changing their minds or for changing the time period. They must **take whatever they can get**. Without options in the community, children are in danger of being separated from their family. The constant care needed and the associated demands of that care cause families to burn out and feel that it would be easier to get services if their children were in institutions, group homes, or other placements.

At the same time, we must tread cautiously when our attempts to provide support and assistance for the child become too disruptive to the family. Support personnel coming into a home to help a child may benefit the child, but having people in your home twenty-four hours a day can be too much for the rest of the family. In these instances, we must look carefully at alternate family arrangements to provide a nurturing and supportive environment for the child while maintaining contact with the natural family. Also, when a child is at risk within the natural family, we must seek alternatives that ensure that both the child's and the family's needs are met.

We do not wish to leave the impression that families are greatly dissatified with the support and services available in the community. We heard of much support and many services that are working well, but families want to see them work even better. Some services like Handicapped Children Services, Alberta Aids to Daily Living, some educational services, and early intervention services have done much to help families and their children. Because of the greater number of children remaining in their communities, however, the **demands far outstrip what is available in the current service system**. There are also a growing number of children with medical and behavioural needs who **require different services and support than those currently available**. It is apparent that more support and services are required and that support and services need to be delivered in a different way if we are truly to meet families' needs.

> *"A family meeting the needs of a person with special needs always finds its resources (financial and physical) stretched to the limit. We often lift the financial burden, but relief and support programs are inadequate."*

We recognize that there are many families that we have not heard from during the course of this Review. There are many families who have their own support networks and resources, have their needs met, and, therefore, do not surface as having unmet needs. There are also families who have requested support and services in some manner through the service system and have received what they needed. We also believe that there are families who have not been connected with the service system because of a lack of information about what support and services are available. It is possible, too, that there are families whose experiences have led them to distrust any portion of the support system, including the Review Committee.

So far, we have discussed those families who have kept their children with mental disabilities at home and in the community. No discussion would be complete without speaking of those families who have children living in institutional settings, group homes, or in other placements. They also have concerns about the service system, but their concerns are different because they believe that many of their children's needs and family needs have been met through **placement**.

Many of these families have come through an era of service that did not provide any choices or alternatives to them. **We recognize the horrendous difficulty of the decision and the stress accompanying the need to place a child outside the family home**. These families made this very difficult decision at a time when there were no services and support available in communities. They may have made the decision as a result of trying very hard to keep their children at home but being unable to do so without help and support. They may have made the decision because they were told that there was no other choice but to institutionalize their children. These families have a great deal of concern about losing the services they currently have. They often **feel pitted against families who have kept their children at home** and feel put down because of the decisions they needed to make as a family. We believe that the decisions made in the past should be respected.

Whatever their situation, families share one common concern. **All families are striving for security for their children**. All families want to know that their children are well provided for, have concerns about their children's future, and want the best possible world for their children. **Security issues** for all families **centre around appropriate personnel** to work with their children, **availability of funding and options, protection from abuse and exploitation, appropriate supervision, standards and monitering, day programs, friends, and accepting communities**. We heard from many parents that **if they could be guaranteed the security** they now experience in their children's current placement **they may**

be willing to look at alternatives to institutional care. Families whose children live at home are also concerned about an unknown future, and they may look at the continued existence of institutions as a threat to their child's future.

Family Support and Assistance and the Future

We believe that all children should grow in a family unit. To this end, we must ensure that support and services are available to help children with mental disabilities and their families.

In our ever-changing world, we must **adopt the broadest definition of family**. That definition recognizes the many different configurations that a family may take and does not judge what is appropriate other than a family meeting the needs of the children in it in a loving and supportive manner. In our discussion here, we speak of children in the home who are under eighteen.

We must also accept a much broader definition of support and services than the one we have traditionally known. We must **make sure that our support and services do not further stigmatize the family** as they express the **need to be recognized, first and foremost, as families**, rather than having to organize everything around the fact that they have a child with a mental disability. Providing appropriate family support and assistance will require a co-operative effort among government, families, community, service providers, and individuals with mental disabilities. Each of these groups has a vital role to play in educating the other groups about their wishes and needs and in outlining the support and services required.

In the future, families must have access to all necessary information about diagnosis, the services available, and options and alternatives.

In the future, family support and assistance must be available and accessible to everyone, but we must realize that support can only be offered. It cannot be imposed on a family. Families must be supported in a sensitive manner, and those working with families must be open to an acceptance or rejection of assistance. Families will have a valuable role to play in formulating policies, developing services and support, outlining the responsibility of various departments, and in maintaining an active and decisive voice about all decisions that affect their children. They must be able to have access to support and services when they are required, and there must not be barriers erected by the services and support systems that were designed to help them. Families will be actively involved in

planning for their children and must have unobstructed access to information, department mandates, knowledge of service systems, rehabilitation techniques, specialists, education, and emotional support. Families must be treated with respect. This means that their knowledge about their children's needs and their own needs is recognized and acted upon by governments, service providers, and departments.

> *"Only families can provide certain vital types of support to an individual with a mental disability. They can do so effectively by having external support from the human services establishment that will enhance and strengthen the family unit."*

As more community services begin to provide service to children with mental disabilities, families will not have to fight for those services. They will be the common practice rather than the exception.

Financial support for families must be provided, but that does not assume that money will solve all difficulties. Support and services in the future do need to respond to the needs of the child, but there is also a need to provide support to the family as a unit rather than focussing on the child's mental disability. Support and assistance must help families see their children in the light of their strengths and weaknesses rather than as problematic and abnormal.

Last but not least, we must recognize the ability of other families to provide emotional and social support. The future must be one in which people with mental disabilities and their families have available to them all of the natural resources and the wealth of knowledge that exist across the communities and people of Alberta.

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services, in consultation with the community, design a provincial policy addressing family support and assistance programs in each region. The purpose of the policy is to:

a. identify essential services which families may need and which must be available in each region,
b. establish parental involvement in decision making about the selection and provision of services, and
c. define the parameters of service options which the department will support and the families may require.

2. That Alberta Family and Social Services, in conjunction with families, develop a plan for each region to support families. At a minimum, the plan must include:

   a. alternative family options to ensure that children are raised in a family environment when the birth family is unable to care for the child. These arrangements should include as much contact with the birth family as possible,
   b. a stated long-term objective of raising children in a permanent family situation with group home and foster care placements used only as short-term accommodation,
   c. developing peer support approaches such as parent to parent programs,
   d. centralized access to information and services for parents, relying as much as possible on joint parental and professional operation of such a service,
   e. a process to critically examine relief services to determine unmet needs, and to develop a range of relief services including emergency relief, in-home and out-of-home relief, babysitting services, shared care arrangements, and recreation programs, and
   f. an orientation toward services which support the family rather than focus exclusively on the person with a disability, e.g. family counselling.

3. That Alberta Family and Social Servies recognize Handicapped Children's Services first and foremost as one of the key elements of family support by establishing a role of lifestyle planning with families which provides families with a decisive voice in determining the needs of their children. This expanded role will necessitate smaller caseloads and will result in the need for additional resources.

For Government:

1. In an era when it is no longer acceptable for Alberta Family and Social Services to assume sole responsibility for services to children with mental disabilities, it must assume the lead in planning with all other departments to ensure that children with disabilities have maximum access to community services on an integrated basis.

Accommodation

"Unfortunately, what is currently available are community institutions—group homes, workshops, and schools—that are physically integrated but not socially and societally integrated."

One of our most basic needs as human beings is that of a home environment. A home not only stands for **stability and comfort**. It also provides us with **opportunities to interact with our neighbours and to be a member of our community.**

Housing needs in the past were met with a specialized response. People with mental disabilities were congregated in a variety of group living arrangements, and varying numbers of people shared the same accommodation. The response to housing needs, then, was to group people within discrete categories of disabilities. The needs of all people within a particular category were viewed as the same. This response has resulted in some people being over-served by their accommodation while other people were under-served. Some people are able to live more independently while others have needs that are not being met.

Accommodation needs have been met through funding by category and grouping people by category. People with mental disabilities who live in the community tend to live with others who are similarly disabled. There is a range of pre-set options available, and people have had to choose from those options. Rather than meeting the need for accommodation, we have tried to meet all needs within the accommodation.

Group homes and facilities have tended to be **training environments**. People have **had to meet entrance criteria** and may be discharged from their residence if they cease to meet those criteria.

People with mental disabilities have had little choice in the people they want to live with or the number of people with whom they want to live. Because of the large numbers of people living together, it is difficult to personalize services. At the same time, there is a limited number of living alternatives. There is a **growing waiting list** of people who want to use the available services, and the waiting list has outstripped availability. The homes available have tended to be staffed by professionals and owned by an agency. Because of the finite resources available, people with mental disabilities have had little choice in changing their accommodation.

Accommodation and the Future

In the future, we presume that children with mental disabilities will grow up inside their family units. Although there is no specific age for when a child would leave home, obviously the focus in the future must be on meeting the housing needs of adults.

The Review Committee envisions a future in which individuals with mental disabilities have the same access to housing as everyone else. Rather than relying on specialized accommodation, we see individuals having access to apartments, condominiums, and rental units and owning their own homes.

In the future, we want to separate people's need for accommodation from the other services and support they may require. The first responsibility is to provide housing for people with mental disabilities. While services and support may be incorporated into the housing, the **home must be a home** first, not a training facility.

Individuals must have every opportunity to **choose the accommodation** they want to live in, as well as **who they wish to live with**. We believe that people with mental disabilities **will not always choose to live with others who have mental disabilities**, so that people with differing abilities and disabilities will live together. We also believe that the future must see accommodation provided on a permanent basis. Individuals must not be expected to graduate from their home environment. They will choose whether or not to live where they live.

We all have to choose our accommodation within the available resources and our income. In the future, people with mental disabilities must be entitled to the same choice. They will handle their own rental or mortgage payments and will establish their own tenant-landlord or owner-financier relationships.

With a wide variety of resources available, we do not see a future where people are on waiting lists or have to move out of their homes because of arbitrary criteria. Accommodation needs must be met in an individual personal manner. Services and support may be available in the home, but these must be based on each person living within the home rather than on the accumulated needs of all people within categories of disabilities. The home must be a living environment that respects in every way the person who lives there.

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services, in recognition that in the long term it should not be offering residential services, develop a flexible governmental policy approach to housing, based on the premise that a home is a home, to form the basis for negotiation with other departments of government to establish the same access to housing for people with disabilities as other citizens.

For Alberta Family and Social Services and community agencies:

1. That the Department of Family and Social Services, in consultation with community agencies, develop a strategy to separate services and support from accommodation needs and to establish residences as homes.

2. That, in accordance with the strategy, residential services be examined to ensure that steps such as the following are taken as interim measures:

    a. For individuals living in group homes not chosen by them, it is incumbent upon the service provider to ensure that:
        i. services are personalized and made for the individual,
        ii. individuals can remain within the home for as long as they choose (entrance and exit criteria be abolished),
        iii. individuals be given maximum opportunity to determine how the home will operate,
        iv. individuals be involved in the selection of personnel,
        v. individuals have maximum opportunity to interact with their neighbors and the community, and
        vi. homes are homes rather than training facilities.

b. individual lifestyle plans are developed with individuals living in group homes to determine if their accommodation needs are being met or if they would like to develop alternatives.
c. individuals choosing with whom they wish to share their home with maximum opportunity for living with people of differing abilities.

3. That a wide variety of options and alternatives be explored with each individual to determine the best way to meet their housing requirements.

For Government:

1. That individuals who require renovations to make their homes physically accessible have access to adequate programs and services to provide them.

2. That financial systems be organized to facilitate individuals with disabilities entering into landlord-tenant and owner-financier relationships.

Individual Lifestyle Planning

"No one should be able to say, 'You are disabled, you've gone as far as you can, be satisfied.'"

Until now, individualization has been focussed on individual training programs through such processes as individual program planning and individual education planning. Typically, individualization began once the person was already inside the service.

Individual Lifestyle Planning and the Future

In the future, individual lifestyle planning will be much broader. It will help people develop a support network. It will step beyond individual program planning and will be the basis for the development of the support and services that individuals require. An individual lifestyle planning process must look at all aspects of a person's life—his or her personality and strengths, needs, goals, and aspirations. As a result, individual lifestyle plans at a minimum should include who the person is, what support she or he requires, how the support will be provided, the financial requirements, and a review and monitoring process.

Including who the person is and what kinds of support and services he or she requires should lead to the customizing of the types of support and services and how the support and services will be provided. The person with the disability must define the kind of support and services she or he needs, where it will be delivered, and how it will be delivered. This approach ensures that the person's disability is not the only reason for the kind of support and services he or she receives.

"Services should be geared to the best interest of the client and with the least intervention."

In a future of a person with a mental disability being fully integrated across society, the individual will have had an opportunity to develop a secure network of friends. These friends, and other individuals in the community, will make up a **personal support network** that will contribute to the individual lifestyle planning process. It may include relations, friends, co-workers, family, neighbours, teachers, and doctors—those people who are important to the individual and who, therefore, can plan the kinds of support and services required with them or for them. Of course, there must be help for those individuals who have been segregated to develop that support network.

> *"Real issues, such as people's self-esteem, development of friendships and support networks, encouragement of self-assertion, planning, and wishing, should be worked on daily."*

The support and services delivered in the future must use a much broader base than they do now. Support and services must be individually customized but will make much more use of the support and services available in the community. They will include specialized support and services only when specialized responses are truly needed. Further emphasis on an individual lifestyle planning process means that support and services must be co-ordinated and managed around the person rather than the person needing to fit into available services.

In the future, people with mental disabilities must have much more choice in who they can look to providing services. All of society's systems will accept the responsibility of providing services and support to individuals with mental disabilities. Individual lifestyle planning must also mean an individual budget negotiated on the basis of one person's needs rather than a group of people with similar needs. In this way, financial planning will take into account the ups and downs we all encounter in our lives and will include planning for these events.

Individual lifestyle planning must not be a static process. As a person's capabilities and needs change, lifestyle plans will need to be updated and reviewed. Monitoring based on the lifestyle plan will ensure that the individual will have a vital role to play in the evaluation and monitoring of support and services. He or she will be much more involved in negotiations for financial resources, the selection of service providers, and the termination of services or support.

Individual lifestyle planning, then, must enable people with mental disabilities to have control of planning their own lives—a natural process for each one of us.

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services, in conjunction with families, consumers, and personal support networks, establish a process for individual lifestyle planning which is consistent across regions so that individuals who move will experience continuity.

2. That the individual, his or her support network, the funding source, and the service provider be included in the process of monitoring and evaluation based on the individual lifestyle plan.

3. That Alberta Family and Social Services establish a vehicle to ensure maximum access by individuals, families, and personal support networks to committees that make the decisions regarding funding of individual lifestyle plans, with their input built into the process. Such individuals should be included on committees that make such decisions.

4. That Alberta Family and Social Services, in conjunction with the communities, develop training, education, and awareness programs for people who will be undertaking the process of individual lifestyle planning.

5. That Alberta Family and Social Services, in conjunction with community agencies, develop a plan to ensure the availability of the lifestyle planning process through resource reallocation, a redefinition of current roles, and the identification of new resource requirements.

For Alberta Family and Social Services and community agencies:

1. That individual lifestyle planning be completed for all individuals already in receipt of supports and services as well as individuals developing required supports and services.

2. That, for individuals who do not have a circle of friends to help them, effort be directed toward development of a personal support network—a key ingredient of individual lifestyle planning.

Educational Services

"I have a right to be educated."

Educational services for children with mental disabilities have operated with the same values and principles of their times. When the primary service was institutionalization, educational services were almost non-existent. At best, educational services operated in some form at the institution.

In the 1970s, when people with mental disabilities began to move into or remain in the community, educational services were provided through specialized schools that separated and congregated people. Then, children with mental disabilities were put into separate classrooms within regular schools. These children were physically integrated but were still separated from the mainstream of the school.

"We find it abhorrent that any adult Albertan should have to go on a waiting list to learn the basic and vital skills of reading and writing."

In the 1980s, there were many more movements within the school system to individualize education plans and emphasize the social integration of children with mental disabilities. Educational services have become more individual and are in a state of transition. We support the move toward full integration.

Educational Services and the Future

The future view of educational services includes children with mental disabilities attending regular classrooms in regular schools and children being welcomed into the neighbourhood school community. There must be a full range of educational

services, which will range from infant stimulation, daycare, early intervention and early childhood services to secondary education. It must include in-home services for children who's health may not allow them to attend school full time. A system of individual funding for educational services must be available to make sure funding is available exclusively to meet the needs of children with a mental disability, rather than general financing to meet the needs of a wide variety and number of "special needs" children.

In the future, children with mental disabilities will be treated first and foremost as children. They must have the right, like all children, to be provided with an education in a home community in a regular classroom with their peers. This kind of education ensures that children with mental disabilities will also learn appropriate social behaviour and will receive an education that includes growth and development with their peers. **All children will benefit from knowing people of differing abilities**. All children must be given an opportunity to **value and respect one another** for the unique individuals they are rather than learning that people who are different must be separated. Integration in education is the first step toward a truly integrated society.

"I love my new classroom. It is quiet. It doesn't smell."

Children with mental disabilities must have an individual education plan with a curriculum that recognizes integration and that includes social skills. A functional curriculum for each student would vary in content, and for some students academic achievement would not be emphasized as much as other areas. This type of education does not assume that children with mental disabilities cannot learn academic subjects. It implies that they may not be as important or, perhaps, as necessary for that person to function fully as an adult.

Teachers cannot be expected to offer educational services to children with mental disabilities without the appropriate support and assistance. **Teachers already have the skills to teach** people with mental disabilities, but **they need the resources** of such people as special education teachers, occupational, physical, and speech therapists, and personal aids.

In the future, education for people with mental disabilities must continue into adulthood. They must be given the same opportunities and access, with support as required, to a wide range of post-secondary education, trade schools, and upgrading.

Recommendations

For Alberta Education:

1. That all educational services be fully mainstreamed within the regular school system with appropriate support available to both students and educators.

2. That the curriculum be adapted to the individual and include functional components to adequately prepare students for adult life.

3. That an individual system of funding be re-created to meet the needs of children with mental disabilities.

4. That a full range of integrated early education services be available to promote growth and development at a young age.

5. That Alberta Education recognize and support the responsibility of school boards to provide education to all students with mental disabilities based on individual needs, including when educational services must be provided in locations such as hospitals and at home.

Training, Employment, and Alternatives to Employment

"There has been a tendency to say that we support people with disabilities. In reality, the community is more comfortable when they are kept in residences and workshops."

Training and Employment

Today, **training and employment services** for people with mental disabilities **are frequently lumped together**. Originally, day activities were part of the care for those with mental disabilities. As values and expectations shifted, training programs were developed to lead to employment. The assumption was that all individuals could move from one level to the other to competitive employment.

Since relatively few people ever made that transition, programs were developed which **simulated employment**, and people could be involved in them for long periods of time. In such situations, individuals could be involved in a training program and an employment program. They would be working side by side doing similar tasks, and the **boundaries between training and employment were unclear**. The general perception was that there was little distinction between training and employment for people with mental disabilities.

It is **no longer acceptable for employment and training activities to be indistinct**. Normally, people go through a variety of types of training in preparation for employment. **Then, training ends.** There may be training on the job for different roles or for advancement, or people may stop doing a particular job for a period of retraining. They do not, however, go through many years of activity that is not clearly defined as training or employment and for which there is only token pay. Nor should people with mental disabilities. In the future, training and employment must be considered separately.

At present, the training system is thought of as employment preparation even though very few individuals move from training to employment. Many individuals spend many years in sheltered workshops, where they produce goods and services but are not paid or compensated for their contribution to production.

Rather than being transitional employment preparation services, **vocational training centres are segregated services**, where people with disabilities are congregated for extended periods of time. **These services do not promote full community integration.**

More recently, **under supported employment, individuals are training on a job site where they can expect to be employed and** where they **are integrated with other workers. This is a step toward the Review Committee's vision of the future.**

Traditionally, employment for those with mental disabilities has been viewed the same as employment for others. That is, the only type of employment for people with mental disabilities is **competitive employment**, in the open labour market, and **without additional support**. This view has been maintained despite the fact that operators of vocational services have been calling for government support for **"sheltered industry"** or **"sheltered employment"** for many years.

Training and Employment and the Future

For most people, employment is the key element that assures their integration into community life. Individuals in the labour force feel valued, recognized, and rewarded. As an employee, a person has an opportunity for decision-making, assuming responsibility, and work-related interaction with other people. This engagement leads to other recreational and social activities.

On the other hand, **people who are involuntarily excluded from the labour force feel, or come to feel, devalued, unwanted, and rejected**. The longer a person is excluded from the work force, the more likely she or he is to experience a **loss of self-esteem**, a **lowered sense of self-worth**, and a **lack of confidence**. That person may withdraw from or may not have an opportunity to engage in other recreational and social activities.

> *"Corporations, by virtue of their visibility, should be leading the way in this area."*

In the future, all training activities must be focussed on preparation for employment in the most direct and effective manner possible. This is the key preparatory step for people with mental disabilities to gain access to employment and all of the benefits that come from it.

In the future, the emphasis must be on training on the job site where employment is likely to occur. The training should be in settings where the number of people with mental disabilities is small and where support services can be developed on site. During the training period, services like **job coaches** must be available to support the individual and to establish relationships with peers, supervisors, and other employees. If other employees leave the job site for further training or retraining, so should those employees with mental disabilities. If that training takes place in training centres developed to provide training that cannot take place on the job site, the participation of those with mental disabilities should be the same as other employees. In the future, however, there is no need for training centres that exist exclusively for people with mental disabilities.

In the future, the services of society that provide training must make themselves accessible to and provide necessary support for people with mental disabilities. This training should be fully funded, or funded to the degree that it is for other individuals, rather than the past practice of requiring vocational agencies to generate revenue to maintain operations.

People with mental disabilities have traditionally been **denied the opportunity to participate in the work force** as full citizens. In the future, their rights must be restored. In order to accomplish this, two groups will need to help implement far-reaching changes. The first group is the **employers**, who must **open their doors** to people with mental disabilities to a much greater degree. The second group is those organizations who now provide training and employment services. Of course, the government must take a leadership role, promoting this new direction and encouraging employers and agencies to adopt this new vision.

In the future, citizens, whatever their abilities and disabilities, must approach employment opportunities in the same way. That is, the first step will be to determine what an individual would like to do. Then, the individual will seek a job that comes close to meeting those desires.

In the future, new approaches in the field of training and employment services will need to be planned. Staff involved in the field will move from being concentrated in segregated settings to community-based support networks for employers and employees who are fully integrated into the community.

"Vocational services have to be restructured to reflect meaningful supported employment opportunities."

In the future, the Review Committee believes that there must be a flexible array of employment options to meet the needs of a variety of individuals with mental disabilities. Some of those options are competitive employment, supported employment, part-time employment, and job sharing. It is the belief of the Review Committee that if training for people with mental disabilities is the same as for society in general there will be an increased number of people with mental disabilities who will be able to obtain successful competitive employment.

Supported employment is an area which has not been included in policy in Alberta and which is desperately needed. There are a wide range of activities labelled as supported employment in various jurisdictions. A series of options to provide support in employment to people with mental disabilities must be developed in Alberta. These options must be distinct from training, must be flexible enough to include the wide variety of supports required by people with mental disabilities, and must be able to adjust to changes in the individual's need for support—be that a decrease, and increase, or a resumption after a period without support.

Other options need to be explored in public policy. Today, for example, the main reason for establishing a business is economic. In the future, public policy must recognize that a reason for establishing a business may be to provide employment opportunities for people with mental disabilities.

Alternatives to Employment

Until now, the service system has primarily recognized the types of training and employment options discussed previously. Most people with mental disabilities have been involved in one of these kinds of programs, and for many there has not really been an identified outcome. For some people with mental disabilities, training and employment may not be the logical outcome of connecting their strengths, needs, and aspirations.

Until now, there has been little recognition or development of **alternatives to employment** for people. **Alternatives** that have been developed have tended to use an approach **based on a person's perceived degree of mental disability, rather than on the individual's choice and identified need for service.**

We have assumed that people who are severely mentally disabled cannot be employed and have developed services from this assumption.

Alternatives to Employment and the Future

In the future, we believe that lifestyle planning must clearly delineate a person's choice, strengths, and needs and the types of employment, training, or alternative services that will best meet a person's needs. It is on the basis of a lifestyle plan that we must develop creative and innovative approaches as alternatives to employment.

The future must recognize a wide variety of alternatives to employment and place value on these alternatives. Alternatives to employment will be highly individual but may include volunteerism, productive leisure pursuits, and pursuit of artistic or cultural activities, to name but a few.

Alternatives to employment must be viable and relevant activities for the person. We believe that the chosen alternatives should provide maximum opportunities for integration, socialization, and maintaining or acquiring of skills and abilities and must be of value to the person and provide opportunities to contribute to community life rather than simply filling hours in a day. Alternatives should be of value to and be valued by society to ensure that people with mental disabilities are engaging in image- enhancing and esteem-building alternatives to employment.

Recommendations

For Government:

1. That adult education and training services for persons with disabilities be mainstreamed into those departments of government that provide those services to the general population. This would include departments such as Advanced Education, Career Development and Employment, and Canada Employment and Immigration Commission.

2. That funding for services designed to address the employment barriers encountered by people with disabilities be extremely flexible to accommodate a variety of individual training arrangements designed to prepare the individual for employment.

3. That a series of supported employment options be developed, established in policy, and funded.

4. That employment be distinct from training and be recognized by real wages.

5. That employment policy recognize that some people with disabilities will require on-the-job support throughout their career.

6. That options for alternatives to employment be recognized, established in policy, and funded.

Financial Systems

"It is necessary for government to provide funding for support services."

Under Financial Systems, a number of methods of financing are discussed: Alberta Assured Income for the Severely Handicapped (AISH), Individual Funding, Program Funding, and Handicapped Children's Services Funding.

Alberta Assured Income for the Severely Handicapped (AISH)

There is a fairly widespread view that AISH is an income for people who are unemployable and that it is a pension for any person with a disability who is eighteen years of age or older.

There is significant **confusion** about the AISH program and what it means to **qualify for it**. For example, most people see AISH as **a secure form of income** for people with disabilities, with higher benefit levels than Social Allowance. Some see it as **a form of entitlement** for any person with a disability who is eighteen years of age or older, and those who hold this view support individuals applying as soon as they are eighteen, even if they are still in high school.

Others view AISH as a **pension** paid to adults with a disability who are **permanently unemployable** and point out that the benefit levels are closer to earning levels at minimum wage than those under Social Allowance. Others see AISH as a **pension** that is **related** to a **disability** and not employability, so they expect AISH recipients to engage in training and/or full-time or part-time employment. AISH also is seen by some as a **choice** some people make to obtain income with **no effort** and, hence, as a **disincentive to employment**.

The provisions of the AISH program to support people who are employed—the major one being the exemption of some earnings—are more generous than Social Allowance. There is the possibility, however, that even with the exemption a person's earnings will be great enough to make them ineligible for the AISH pension and the associated benefits such as health care. For individuals with mental disabilities who receive AISH, losing it can be a significant **threat to security**. The employment may not be stable or enduring, and the reinstatement of AISH benefits may be difficult or impossible if employment is lost.

Some agencies and organizations who are attempting to provide training for people with mental disabilities have gone so far as to consider AISH recipients **ineligible** for their **services** because of their beliefs about AISH. For example, Alberta Career Development and Employment considers AISH recipients unemployable and, therefore, ineligible for their Vocational Rehabilitation of Disabled Pensions (VRDP) Training Services. As well, some community colleges do not admit AISH recipients to their transitional training programs.

The Review Committee is concerned because the amount of the AISH pension is standardized and does not reflect individual need. The result is that some individuals may be receiving more income from this source than they require and, certainly, many are receiving considerably less than they need. If an individual wants funding based on individual need for support and services, he or she must go the route of Special Needs Social Allowance. This means giving up the AISH benefit. As well, eligibility for the Special Needs Social Allowance is dependant on continuing need, which is another level of insecurity and another disincentive to moving beyond the AISH pension.

AISH and the Future

There are at least **two routes** the AISH benefit could take in the future. AISH could be established as a pension provided to people with mental disabilities. It would be **like Old Age Security** and would **not be affected by income** or other financial circumstances at the time the cheque is provided. The suggestion is that employment earnings would not reduce AISH but would be considered in the income tax system.

An **alternative approach** would be to have AISH benefits as a **source of income for individuals** with a disability **who are unable to secure and maintain employment**. An individual would need to have **exhausted** all rehabilitation

opportunities and employment options before an AISH pension would be granted, and it would mean that the **individual is not expected to work**. Individuals who are employed full or part time would be removed from the AISH program. This approach would address the disincentives to employment in the present program, but it would reduce the income protection for individuals with mental disabilities who are expected to work and who currently receive AISH.

Individual Funding

What has been happening more and more within Alberta Family and Social Services is that individual lifestyle plans are being developed. When they are complete, financial support is sought. The method most frequently used by Alberta Family and Social Services to **fund individual lifestyle plans** is **Special Needs Social Allowance**, also known as AISH+ or AISH type 1. Individuals who receive AISH and who develop an individual lifestyle plan must then relinquish their AISH payment and roll over to Special Needs Social Allowance. Social Allowance, a mechanism which has been developed as an antipoverty device, is being used to support services because they are defined as a special need.

Individual Funding and the Future

In the future, a mechanism for individual funding to support citizens with mental disabilites is required. There are a number of characteristics which the new mechanism for providing funding must possess. It would be a specialized appropriation of funds, to support individual services and provide a pool of funds to be distributed on an individual basis rather than supporting programs. As well, funds would be available on the basis of an individual lifestyle plan developed by the person with a mental disability and his or her support network. Based on a comprehensive twenty-four-hour plan, the needs of the individual would be identified, the source of the services would be specified, and the cost of those services would be determined.

> *"Future service development should continue to develop with the direct input of the consumer and their family, reducing the need for block funding and allowing for individual funding mechanisms."*

This fund must include the provision of payments to individuals who would purchase their own services. It would not be a requirement that the department or administering agency purchase services on behalf of an individual. The fund must support a wide range of services, reflecting the individual choices of the person with a mental disability. Those services could include training, employment, recreation, socialization, and complete community integration. The fund must be able to support highly individual lifestyle plans that are not subject to arbitrary cost limits or arbitrary time constraints. The source of the fund must be secure and subject only to revision as the needs and choices of the person change.

Program Funding

In the past, funding was provided to community agencies, by grants or contracts, to support programs offered by them to people with mental disabilities. Some agencies offered one or two programs while others offered a wider range. Programs tended to be defined by the level of the individual's needs and the type of training required to meet those needs. The most commom programs funded throughout Alberta were residential and vocational programs.

The services offered under this funding model were segregated, congregated services to people with disabilities. Selection for program funding was based on matching the agency offerings to the perceived needs of similarly disabled individuals applying for service.

Program Funding and the Future

In the future, when citizens with mental disabilities are more integrated into the general community, there will be significantly less need (if any) for this type of service. There may well be a need for program funding, however. In the future, program funding could be based on providing essential support for community agencies. They could offer support services to individuals who would pay for the services out of individual funding.

Another approach would be for the programs themselves to offer individual funding services. This could be done by having an allocation provided to an agency to be distributed on the basis of approved individual lifestyle plans. Rather than controlling the day-to-day expenditures of the fund, an agency would turn it over to an individual based on the lifestyle plan approved through the agency and departmental process. In either case, program funding must change

from support of segregated, congregated services to making sure that there is expertise in the community for developing, implementing, and supporting individual lifestyle plans.

Handicapped Children's Services

This program offers an individual approach to funding for services to children with mental disabilities. Difficulties with the program have centred around accessibility to the program, the availability of information about the program, and the consistency of administration. One of the issues related to Handicapped Children's Services is the present practice of having service plan development and financial resource allocation handled by the same individual. Arguments have been advanced for a separation of these two functions.

Handicapped Children's Services and the Future

In the future, when significantly increased support to families is a priority, access to information about the range of financial support available for the program is paramount. The range of services that can be supported in a variety of circumstances needs to be balanced with the particular needs of one particular child in one particular family. Families must get essential and necessary support early, to maintain family and community integration.

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services examine the AISH program within the context of promoting full citizenship, clarify the intent of the pension with respect to employment expectations and financial support for necessary services, and implement necessary modifications.

2. That Alberta Family and Social Services examine the Handicapped Children's Services Program, determine an appropriate role for program staff in developing individual lifestyle plans, determine if that function should be separate from resource allocation, and develop a plan to promote access by families to information, lifestyle planning, and appropriate financial support.

For Government:

1. That Alberta Family and Social Services, in conjunction with Alberta Treasury, establish a budget element for individual funding for support and services, with mechanisms to disperse funds on an individual basis, including payments to individuals to purchase their own services. Funds currently being spent for this purpose under Special Needs Social Allowance must be transferred to this new element and supplemented by additional amounts to support development of individual community-based services.

2. That Alberta Family and Social Services, in conjunction with Alberta Treasury and community agencies, develop a plan to reallocate current budgetary provisions for program funding to the new individual funding element. This plan must ensure the reallocation is staged to ensure that those with the expertise required by people with disabilities are able to adjust to individual funding and continue to provide needed support and services.

3. That Alberta Family and Social Services, in conjunction with Alberta Treasury, establish a budget element with mechanisms to disperse funds on an individual basis for emergencies, where individuals confront financial barriers due to disability and which could not have been predicted when the lifestyle plan was developed.

Agency Roles

"Many of these agencies have built up a high, positive profile within that community. They have established rapport with other human service agencies as well as community businesses, shops, and services. Some have well established boards of directors and a bank of community volunteers. This base of service delivery could be used as a structure from which to develop more innovative, individual service delivery options."

Agencies have played a vital role in the delivery of services to people with mental disabilities in Alberta. The vast majority of hands-on services outside institutions have been provided by a wide variety of agencies dedicated to all aspects of service provision, be it accommodation, vocational programs, recreation, or specialized care. Most of the community-based agencies began because of the concerted action of concerned parents who saw a need for an additional service or support. Frequently, the results of their efforts were funded by government and by communities.

There is a wide diversity of philosophical stands and organizational structures among service providers. Many agencies are firmly committed to empowering the individual as much as possible. Others work in the traditional mode of the 1970s.

Over the years as agencies grew, particularly in the larger centres, parents were often replaced in positions of influence in the agency such as on the board or in key staff positions. Parents began to feel that they had lost control of the services. In many cases today, parents feel that agencies have a life of their own and that they must accomodate the agency's wishes or their children will be left without services.

Agencies have the difficulty of working within a system which makes them servants of several masters, often with conflicting requirements. They have to try and serve the consumers, the family or guardians of consumers, their own mandates, the community at large, and Alberta Family and Social Services, which often places increasing demands on them with ever-decreasing resources.

> *"It is hard for small agencies to hire and keep staff with the amount of money they can pay people."*

Departmental fiscal policy is causing severe problems for agencies. We deplore the current situation in which many people who provide the most intimate and personal services to people with mental disabilities are paid little more than the minimum wage and have few, if any, career prospects. As well, there are a number of areas in which agencies have been frustrated by the unrealistic demands placed on them by a government unsure of its own role in the provision of services to people with mental disabilities.

Many parents and guardians fear an instability and lack of permanence when institutions are closed and people are living in the community, regardless of mental disability. We expect agencies to provide this security and permanence by diversifying their roles in many more areas where they can provide experienced leadership. We recognize that many agencies have started to develop these roles. They must be encouraged to continue. While in the major urban centres there is a diversity of agencies providing a multitude of services, in the smaller communities there is often only one agency providing as wide a range of services as its mandate allows.

Agency Roles and the Future

In the future, we see the role of agencies changing to recognize a consumer-driven service, supported by family, personal support networks, community, and government. We see agencies providing leadership in the move toward supported employment and toward helping people with mental disabilities acquire and remain in their own homes.

In the future, we would like to see a much more co-operative role between government and agencies, driven by the demands of the consumer and supported

by their families and the communities in which they live. We would expect government policy and legislation to recognize the value of people with mental disabilities and, consequently, value those who provide services to them. We see caregivers and service providers being as valued in the community as nurses and teachers, with all that implies, including defined career paths and adequate resources.

We would see the establishment of **more**, and probably **smaller**, **agencies governed by consumer demand**. The Committee approves of the move already established in some areas of Alberta. There, private for-profit agencies work alongside not-for-profit agencies to provide a diversity of services. Of course, all agencies should be subject to the same **licensing requirements**, which would include regulations to ensure continuing service should any agency close its doors or change its mandate.

In the future, **agencies** will have a **vital role** to play **in support and services provision**. Their **roles may be different** from the present and must incorporate such functions as:

— job coaching and supported employment programs
— brokering services and staffing, for such things as helping find accommodation and staffing
— developing initiatives to ensure greater community awareness and acceptance of people with mental disabilities
— providing leadership in the expanding roles of volunteers and friends
— providing homes for more than one person as an accommodation option
— being a source of specialized services for those who wish to develop other living options
— providing a leadership role of recognizing and valuing those who provide services to people with mental disabilities
— working with government and other community services to establish career paths for qualified staff
— advocating with community service and government agencies
— providing relief and respite services
— helping with lifestyle planning
— providing family support
— helping the development of self-advocacy groups and developing more consumer-oriented and consumer-involved services .

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services establish advisory boards composed of a representative cross-section of consumers, personal support networks, advocates, service providers, and the community at large to foster co-operation in service delivery and monitoring, to ensure government policy is implemented at all levels, and to establish uniform minimum standards throughout the province.

2. That Alberta Family and Social Services establish a system of licensing and monitoring for agencies providing services to people with mental disabilities.

3. That Alberta Family and Social Services promote the development of courses and training programs at post-secondary institutions to produce staff qualified to meet the needs of persons with disabilities in a variety of services, and that funding to service providers be increased to recognize those with qualifications.

4. That the funding provided by Alberta Family and Social Services encourage a diversification of service providers who, in turn, must give choices to the person with a mental disability from as wide a variety of services as possible.

Institutional Services

"If we are to will a future of inclusion of persons who are disabled or persons who are simply different, then they must be 'in' our presence. The philosophical position we take in viewing the present and future services in Alberta is one founded on the real and tangible value of the human person, alive and present where people normally live."

Institutional services for people with mental disabilities began in Alberta in 1923. That year, the Provincial Training School opened, later to become the Michener Centre. In the early years, little training or skill development was available. **Institutions existed to protect people** from society and keep them well cared for and happy. **Constant demand** for this service resulted in **overcrowding** and **waiting lists** and new buildings were erected to meet growing needs.

As early as the 1930s and 1940s, there was some emphasis on training, but it was not until the 1960s that institutions made a true commitment to training people. Through the 1970s and 1980s, there was an even greater emphasis on training and normalization.

During the 1970s, two new smaller institutions opened in Alberta, bringing the total to four. The greater number of institutions allowed some residents to move closer to their families rather than living in Red Deer. In **1970**, the **Michener Centre** was **serving over 2,200 people.**

With the publication of the Blair report and the government's **commitment to de-institutionalization and normalization in the 1970s,** community-based services were developed. There has been a **steady decrease in the number of residents** in institutions, one centre has closed, and there have been **few people seeking admission**.

Institutions played a valuable role in the development of services for people with mental disabilities. In a time when we knew little about people with mental disabilities, institutions protected and cared for them in a closed environment. However, people with mental disabilities have adequately demonstrated their abilities to live in the communities, as is their right.

Institutional Services and the Future

In a future based on full citizenship and total integration into the community, there will be no need for institutions to provide services for people with mental disabilities. In an era of total integration, it will no longer be seen as appropriate to segregate and congregate individuals based on the sole fact that they have a mental disability.

In the future, people with mental disabilities must have the same access as other people to institutional services like educational institutions and health care institutions such as hospitals. These institutions are operated and funded by those departments of government responsible for those services to all citizens (for example, education and health). Alberta Family and Social Services will not operate institutions in the future.

The Committee is compelled by the need to restore the rights of citizens with mental disabilities and is convinced that there is a sense of urgency to do so. This is a new vision and a new understanding and is not a condemnation of decisions made at an earlier time. The individuals and communities who dedicated themselves to providing the highest quality service in those service systems will no doubt be able to make equal or greater contributions to the new approach of citizenship and full integration.

> *"We put criminals in institutions. I am mentally disabled, not a criminal."*

An aggressive approach to replacing institutions with community-based services is required. For all institutions, an accelerated pace of replacement must be established.

The **replacement of institutional services** by community-based services **must be done in a carefully planned manner** that includes the support necessary for

integration into community life. **It is unacceptable to move people into the community without essential support** so that their quality of life actually suffers rather than being improved by the move. Experiences in other places give us examples of the human suffering that results from replacing institutions without creating community support.

There are a number of important factors to consider:

— In determining the cost of replacing institutions with community-based services, the essential nature of **transitional funding** must be recognized. This funding will be required to develop a support system for each individual. The support system must be in place before an institutional resident leaves the institution.
— With our understanding of the future, we must not put individuals in situations where their rights are abrogated. **No further admission** to any institution for people with mental disabilities can be tolerated.
— The service system must be constructed in such a way as to **accomodate change** in the lifestyle of people with mental disabilities, whether that change is the result of individual choice or an external factor.
— The **standards** for community support must be set by the individual citizen with a mental disability and with her or his support group. **Monitoring and evaluation** of community support also must depend heavily on the individual and the support group.Standards need to be established by government to guide individual lifestyle planning. With the shift to individual services and choice, it will be necessary to examine the role of various stakeholders in the monitoring and evaluation process.

Recommendations

For Alberta Family and Social Services:

1. That Alberta Family and Social Services develop a strategic plan of replacing institutions with community-based services. The strategic plan must include the components necessary to ensure that a minimum of 20 per cent of the residents of each institution be relocated to a community each year.

2. That the preference of residents of institutions be a major consideration in identifying individuals to move from an institution to a community. Priority must be placed on planning for and relocating all residents, including those with a high need for support services.

3. That institutional services not admit or re-admit any further residents. Community-based support must be developed for all citizens, whatever needs they have.

For Alberta Family and Social Services and the community:

1. That for each institution, a specialized unit committed to the depopulation of that institution be established. These units must be provided with the responsibility and authority to plan, with support services in the community, the move of individual residents to a community setting. Staff from community agencies are to be involved in the planning process prior to the move of the resident, and the specialized unit will follow up in the community until the support services are stable and secure.

2. That planning for individuals who move from institutions to a community include back-up support systems to insure security in the community.

For Government:

1. That transitional funding be established to cover the cost of the community-based support services that will be required to receive residents of institutions. This funding is transitional because additional expenditures are necessary on a time-limited basis. As institutions reduce in size, the budget for institutional services can be reduced, then eliminated.

Recreation

"The right to participate is seen as a shared responsibility of government, individuals, families, and corporate citizens as well as people with disabilities themselves."

Recreation is an important aspect in everyone's life for a variety of reasons. We gain physical fitness and health from physical activities, and recreation provides us opportunities to have fun, gain self-confidence, and enhance our self-image outside of structured school or work lives. Recreation also allows us to meet a wide variety of people, develop friendships, learn new activities, be creative, and to grow and develop. We can have competition and fun in areas that interest us, meet our aspirations, and challenge our abilities. We choose our recreational activities.

In the past, the tendency has been to see recreation for people with mental disabilities as part of a rehabilitation process or as a series of programs. People with mental disabilities were thought to require specialized recreation activities in locations specifically for them and separated from the rest of the population. They were seldom allowed to choose their activities.

In many instances, people with mental disabilities have limited access to community recreation activities. They tend to be involved in very structured, imposed activities based on the direction of others, or they may be able to choose from a limited number of activities. They are often limited to activities such as bowling or swimming rather than having the choice of a wide range of activities that the general population takes for granted.

Recreation in the Future

In the future, we believe that people with mental disabilities must be given the choice of a wide range of physical fitness, clubs and organizations, creative endeavours, cultural activities, and tourism services. They have a right to these services, to pursue recreation with all other citizens, and to be accepted as an equal community member. Adaptations to existing facilities may be necessary to make sure people with mental disabilities can pursue their chosen activities, but they **do not need specialized locations or activities to meet their interests**. To ensure equal access to recreation, society will need to recognize the right to access, adapted rules and regulations, physical access, and information.

While we support the full integration of people with mental disabilities into community recreation, we must also recognize that organizations such as the Special Olympics have a vital role to play. By its very nature, competitive sport puts together individuals with similar levels of ability to challenge each to excel while maintaining a fair level of competition. People with mental disabilities are entitled to the same thrill of competition as other citizens. Organizations such as the Special Olympics need to be recognized as an equal partner in the sporting community, and the competitors must be included in the locations and mainstream of competitive sports.

Recommendations

For Government and community agencies:

1. That the primary determining factor in selecting all recreation activities be the expressed interest of the person with the mental disability.

2. That departments such as Alberta Recreation and Parks include people with mental disabilities in their mandates and involve them in their planning for facilities and activities.

3. That where recreation facilities are not physically accessible, they be renovated to make them so.

4. That barriers to full and equal access and participation in recreation activities must be removed and adaptations made to ensure all who wish to participate are able to do so.

5. That sport training and competition be available for those citizens with disabilities who wish to pursue this type of recreation.

6. That all mainstream competitive activities must examine their competitions to determine how citizens with mental disabilities can be included in both integrated and parallel competitive events.

7. That summer recreational programs for the general student population must make themselves accessible to people with mental disabilities, so that specialized, segregated programs can be terminated as individuals have access to integrated programs.

Transportation

"How can I participate if I can't get there."

Throughout the province, people with mental disabilities **do not have adequate transportation services**. In urban areas, people who are ambulatory do have access to regular transportation systems, but in rural areas this option is not available. For non-ambulatory people, services are not available nor is there access to them outside of traditional work hours. In rural areas, people with mental disabilities often have no service other than school buses, which are not appropriate for adults and which do not operate at the times and with the frequency required to support adult lifestyles.

In the past, some funding for transportation has been available through a variety of municipal grants and service groups. However, there is no consistency of service nor is there the desire to provide service in many areas of the province.

We applaud the efforts of families, staff, and friends to meet the transportation needs of people with mental disabilities. However, we believe that **no one should have to rely on the good will of others for a service as essential to community integration as transportation.**

Transportation and the Future

We believe that the availability of transportation is vital to the full integration of people with mental disabilities. It is quite impossible for people to work or use recreational facilities and community programs and services without transportation. At the same time, like the rest of the population, transportation needs do not end at the finish of a work or school day and transportation for people with mental disabilities should be available outside of business or school hours.

Transportation services such as planes, trains, and buses must recognize the needs of people with disabilities and must provide appropriate physical adaptations.

Recommendations

For Alberta Transportation:

1. That Alberta Transportation work in conjunction with the municipalities and consumers to ensure that funding is available to provide adequate transportation services across the communities of Alberta.

Medical Services

> *"My child was nineteen months old before she was diagnosed. If she had been diagnosed earlier, we could have had her in programs earlier. The earlier a child is in a program, the better are that child's chances down the road."*

Many families have children (most of whom are adults) who do not live in the community, and they are afraid that their children will not receive the excellent medical and dental services that they now receive in institutions. These families question whether or not institutional services can be replicated in the community. They are also concerned about the administration of medication and the monitoring of health needs if individuals move to homes in the community. Families outside of urban areas have the added concern about access to medical specialists and the distances they must travel to get to specialized services.

Some medical services, and in particular many medical doctors, are not aware of options for people with mental disabilities outside of institutionalization. Doctors do not inform families of the capabilities of people with mental disabilities, and, often, families are given all negative information about their children. At the same time, although doctors and dentists are willing to provide services to people with mental disabilities, the extra time sometimes required and the fee structures do not acknowledge additional services. In dental care, the fees provided are inadequate for preventative treatment.

There is **limited prenatal education** and information about **research** and limited **genetic counselling** about children with mental disabilities and what causes those disabilities. There has been a general unawareness of cause and effect in the community.

Medical Services and the Future

As more people live in their home communities, people with mental disabilities are being accepted as patients and treated the same as any other person. At the same time, there must be a recognition of specific treatment and the necessary time for and cost of such treatment. Doctors must have more information about the options available for families of children with mental disabilities.

Prenatal education about proper nutrition, the avoidance of alcohol, smoking, and the use of drugs, both prescription and non-prescription, must become more important. There must be more awareness of the existence and availability of genetic counselling services and prenatal obstetrical diagnostic techniques.

Recommendations

For Government:

1. That Alberta Health continue to address the prevention of disabilities through the availability of genetic counselling, prenatal education, and research.

2. That medical and dental fee structures be examined within the context of the special needs of people with disabilities. In situations where more time is required, allowances should be made. Where early preventative measures will address what would otherwise be remedial services later, they should be covered.

3. That government, professional associations, and representatives of citizens with disabilities review the present access to specialists in areas other than large urban centres. Options to enhance and plans to improve access should be developed, including measures such as toll-free lines and travelling clinics.

4. That medical and dental practitioners now attached to institutions be considered a valuable source of education and should be viewed as a resource for community medical services.

Advocacy

"Every service available to other people living in the community should be available to people with mental disabilities."

Until now, **defending the rights of citizens with mental disabilities and promoting their interests has been a function of service agencies and promotional groups**. These organizations have spoken for individuals with mental disabilities and have done much to further community awareness and acceptance, lobby for services, and promote rights. Many organizations have had to maintain the delicate balance of providing services while advocating on behalf of individuals and groups of people.

"Due to a lack of awareness of individual rights, mentally disabled individuals often are unable to speak up or are not allowed to."

Individuals with mental disabilities have had many people speak on their behalf, but they **have had limited opportunity to voice their own opinions** about the organization and development of services. They have **not had an active voice in decision-making** nor have they had the ability to **influence decisions made on their behalf.** Individuals are compromised when they are receiving services from an organization that is often advocating for them as well They have had no ability to have their opinions heard or responded to by the organization.

Because people with mental disabilities are a small percentage of the population, they will be a small number within any group with similar interests and are further handicapped by this small representation. When individuals are involved in advocacy organizations, they are **seldom in positions of leadership and are a recipient rather than a contributing member of the process**. This position leaves them virtually **powerless to speak for themselves.**

Promotional groups and agencies have been hampered by a lack of funds to adequately promote the interests of people with mental disabilities. People with mental disabilities are also unable to finance these groups in the same way that other advocacy groups can raise funds through such means as collection of dues and meeting fees. There is some evidence of consumer groups inside service agencies, but this has been the exception rather than the rule.

Advocacy and the Future

We have seen the effectiveness and influence of self-advocacy. In the future, self-advocacy and self-determination must be encouraged, supported, and facilitated. The recognition of true and equal participation for all citizens must begin with self-representation and an active voice in all of the decisions that affect the lives of people with disabilities. People with mental disabilities must no longer be represented by others when they are capable and willing to assume this responsibility for themselves.

The **ability to advocate will require support**, as this is a new role for many people with mental disabilities. They may have become accustomed to others speaking on their behalf. We believe, however, that it is critical that people with mental disabilities recognize their ability, right, and responsibility to speak for themselves.

People with mental disabilities are often also **handicapped by a lack of information, little experience in group participation and organization, few or no leadership skills, and communication processes that do not recognize different methods of communication.** They should be given ample opportunity to learn these skills and have the exposure and experience of self-advocacy. As people learn these skills, they will become much more comfortable with them. When they experience the results of self-advocacy and the ability to influence decision-making, we believe that the participation and exercise of this right will flourish.

Organizations that currently advocate on behalf of people can do much to foster self-advocacy by critically examining their practices and roles and by being sure that **people with mental disabilities begin to assume the roles now performed by others**. Service agencies also can foster self-advocacy by including consumer input and decision-making at all levels of their organization, from board representation through to deciding about services and approaches.

Individuals with mental disabilities can **help one another by becoming involved in self-advocacy movements** and by representing those who may be less able to articulate their own interests. We realize that some people may need to be represented by support people, but we believe that this role should be taken on by consumer-advocacy groups so that all people with mental disabilities have an **active voice in promoting their rights and interests.** For those support people who represent people with mental disabilities, it means **constant vigilance about whether or not they are listening to and representing the citizen with a mental disability rather than expressing personal preference**.

The role of agencies and groups must change to one of facilitation and support rather than advocacy. Advocacy groups should be led and managed by people with mental disabilities.

In the future, we envision an exciting movement of self-advocates who will speak and lobby on their own behalf and will have a true voice that is heard through all levels of decision-making.

Recommendations

For Alberta Family and Social Services:

1. That financial resources be committed to assist self-advocacy groups to form and maintain themselves.

2. That support and assistance be provided to help persons with mental disabilities form their own self-advocacy groups and provide a mechanism by which their voices will be heard.

For Alberta Family and Social Services and community agencies:

1. That agencies and institutions have consumer advocacy groups who have input at all levels of the organization and the ability to participate in and influence decision-making.

Guardianship and Trusteeship

"People with disabilities should expect to be able to be full and equal participants in all aspects of their daily lives and in community involvement. This standard should restrict the availability of guardianship orders and should facilitate their challenge once the order is made."

Throughout the Review, it became clear that there is much **confusion about guardianship**, particularly in the execution of the role and the responsibilities of a guardian. There are concerns about **how easy it is to obtain guardianship,** about the **conflict of interest** between the dependent adult and his or her guardian, about the **costs** and the court procedure for obtaining guardianship, and about the use of guardianship as a **control mechanism** rather than a mechanism that supports dependent adults in influencing choices and decisions about their lives. There were fewer concerns about trusteeship. The necessity for a trustee in most cases was not questioned, but there are concerns about the inflexibility of the system and the demands placed on **private trustees** in the area of **accountability**.

Until now, many have felt that guardianship is a formal process to extend parenting, and there seems to be a significant lack of understanding about the differences **between being a parent and being a guardian**. Many see these roles as the same, but we do not believe that this is the intention of guardianship

When looking at Public Guardianship, there are a number of issues to consider. First, the **caseloads are so large** that there is **infrequent contact** with dependent adults and a general view that Public Guardian representatives do not know the dependent adults for whom they are guardians. Second, the Public Guardian representatives are **concentrated in major centres**, and people with a mental disability have difficulty reaching their guardian representative, particularly in a short time. Third, reorganization and turnover in Public Guardian representatives

results in several different representatives being involved with the same dependent adult (sometimes, over a short period). Finally, there is a perceived conflict of interest with the Public Guardian reporting to Alberta Family and Social Services.

It has been unclear until now what the **role** of Public Guardian representatives is **in lifestyle planning, advocacy, case management, and day-to-day interactions** with dependent adults. It is unclear what level of responsibility representatives have in participating in those processes rather than simply approving or disapproving the efforts of others. With regard to the Public Trustee, concern was expressed about the amount of control exercised and the fact that the relationship to the person with a disability was impersonal. **Trusteeship orders are easy to obtain and difficult to terminate.**

Full guardianship rather than partial guardianship for people with mental disabilities seems to be the most common. At the same time, once a guardianship order is in place, a review of that order is an automatic renewal of the order. It is seldom seen that guardianship should apply only in the areas where it is essential or that if it is no longer required the individual should cease being a dependent adult.

The person for whom the guardianship order is sought does not appear to have a say in the process and does not have legal representation before the court. On the other hand, the person applying for guardianship has a legal representative who frequently is there to represent both parties. This seems to be a basically untenable position.

Guardianship and Trusteeship and the Future

The issue of guardianship in the lives of people with mental disabilities is a concern for the Committee. Any process that removes rights from citizens is a very serious one and cannot be taken lightly. The confusion that exists about guardianship and the ease with which an individual's rights can be abrogated are unacceptable.

We believe that guardianship has its merits and, in many instances, is a required support. In the future, we hope that individuals will have more control over their own lives and that, in particular, Public Guardianship will decrease as individuals develop and maintain relationships that can assist them, rather than having to rely on state protection and support.

Recommendations

Guardianship

For Alberta Family and Social Services:

1. That a complete review of guardianship and the Dependent Adults Act be undertaken to examine the concepts of citizenship and equality of human and civil rights and to identify any changes necessary to support those concepts.

2. That the person with a mental disability have an independent legal representative (court appointed) in any proceedings concerning guardianship.

3. That there be clarification of the responsibilities and role of the guardian to ensure that the order enables the person rather than simply controlling her or him.

4. That there be an investigation into how individuals who have a guardian can retain dignity, ability of choice, and self-determination in areas of their lives that they can learn to manage for themselves.

5. That appeal routes be established for the individuals who are in conflict with their guardian about decisions made by the guardian.

6. That there be a representative of the Public Guardian located in communities where the number of dependent adults constitutes a caseload, and that representatives be present in smaller communities so that dependent adults have easy access to the representative when required.

7. That there be training programs for all people who are to become guardians (whether public or private) to ensure the understanding that guardians have responsibilities, not rights, and that the person's interest will be represented, not the guardian's.

8. That there be an interaction between the public and private guardians in the roles of watchdog, training, education, and fulfillment of duties.

9. That there be a review of the legal fees involved for private guardians and a clarification of when and for whom legal representation is required.

For Government:

1. That there be an examination of the perceived conflict of interest with the Public Guardian reporting to Alberta Family and Social Services.

Trusteeship

For Government:

1. That simplified accounting procedures for private trustees be examined and implemented.

2. That learning control of personal finances should receive high priority for people with disabilities.

Education and Awareness

"My youngest cousin was born with Down's syndrome. At the time, the rule was to cart off such children to the unknown. His parents didn't register his birth, and they decided he was to be treated like other children. There was a family rule that he was to be included, so that when we played baseball he was included, and not just in the field. He had to take his turn at bat, as well. When he was crying on the steps of the school, we simply brought him in and included him. He lives a sheltered and supported life. He is now forty-nine and has a quarter section of land that he farms. He was never taught that he was any different than anyone else."

The attitudes and values about what is normal and what is not probably play the largest role in determining whether or not a person will become handicapped.

In the past, society learned to fear people with mental disabilities or felt that they must be segregated from the rest of society. There was little or no understanding that people with mental disabilities had the same rights, privileges, and responsibilities as the rest of society.

Most of the attempts at public awareness have come through advertising campaigns that typically have been appeals for funds. While this type of advertising has been successful for fund-raising, it has relied too heavily on the image of people with mental disabilities as needing charity or pity.

Today, attitudes are changing. They are changing in part because people with mental disabilities are no longer being shut away. Replacing institutions with community services is introducing many people with disabilities to the community and the community to them. Attitudes are also changing because of a

heightened awareness throughout society of people with disabilities. There was considerable media coverage of the fact the people who are residents of institutions have been given the vote. The names Terry Fox and Rick Hansen and the movie *Rainman* need only to be mentioned. The vote, two names, and a movie are representative of a change in society, an awareness in society.

The Brassard Committee, itself, is a sign of change. The Committee came into existence and evolved because of heightened awareness and a demand, a hunger, and a need for change.

Education and Awareness and the Future

In the future and beginning now, Alberta must do some serious work about **raising the consciousness** of all of society. Awareness and education must be image-enhancing for people with mental disabilities and must focus on equality and citizenship rather that on differences and separation. Active steps must be taken to educate the public, the people with mental disabilities themselves, community service providers, and specialized support services. It is critical that people with mental disabilities be given every opportunity to speak, promote, and educate on their own behalf rather than having others do it for them.

> *"Acceptance is not created by need but, rather, by hard work, education, and time."*

This education will be necessary only in the short term. As families keep their children at home and all children grow and develop alongside one another in the schools and the community, the acceptance of people with different abilities will become natural and the social norm.

In the future, all people growing up in an integrated world will naturally accept the co-existence of people with mental disabilities in our neighbourhoods, schools, jobs, recreation, and community services. The next generation will not have grown up in a segregated world, and, consequently, many of the issues facing all of us will not be issues of the future.

Recommendations

For Government:

1. That the decade of the nineties be a time for the Governnment of Alberta to commit resources to create public education and awareness programs promoting equality and citizenship at both the public at large and specific groups, including self advocacy and consumer groups.

2. That public education and awareness programs assist all systems of society to recognize and respond to their responsibility to provide service to persons with mental disabilities.

3. That education programs be developed that will assist persons with mental disabilities to be informed citizens and to make choices based on their knowledge.

4. That an education and awareness program be developed for public health units and social workers in hospitals to ensure that families have access to timely and accurate information and assistance at the time of birth of a child with a mental disability (or at the time of diagnosis).

5. That an education and awareness program be developed addressing all services in the community that now provide accommodation, which emphasizes their responsibility to provide these same services to individuals with disabilities.

6. That an education and awareness program to encourage employers to hire people with disabilities be developed to increase the number of employment opportunities.

7. That an education and awareness program, designed to make accessibility easier, be targetted to all organizations that provide recreational activities in communities.

8. That an education and awareness program regarding the philosophy of citizenship and equality within all medical services in the community be established. Provincial medical associations, public health units, hospitals, municipal social service departments, service providers, and Alberta Family and Social Service must collaborate in such programs.

The Legal System

"I should have to go through the same legal process, even if the punishment is adjusted because I have a mental disability. To do otherwise discounts my worth."

When citizens with disabilities have become involved with the legal system, as the accused, a witness, or a victim, they are treated differently from other citizens. We have heard of situations where people are not prosecuted because they have a mental disability, are denied parole or probation because of their mental disability, and do not receive justice when they have been victimized.

The Legal System and the Future

All citizens, including those with disabilities, are guaranteed equality before and under the law. We believe that society must make sure that people with mental disabilities are given equal opportunity to be heard and understood and to have the courts understand the nature of a mental disability as it may influence evidence or the understanding of the facts of a case. They must be given due consideration under the law as witnesses or as victims. People with mental disabilities who have committed crimes must also be treated as equal citizens, and their punishment cannot be lessened or increased simply because of their mental disability. They must have equal treatment in prosecution, parole, and probation.

So that people with mental disabilities are treated equally under the law, the legal system may need to make extensive use of other means of communication, interpreters, and translators. Communication should be adapted to ensure the awareness of the rights of a person with a mental disability as a full citizen.

Recommendations

For Government:

1. That an education program focussed on the legal system be developed, emphasizing that people with mental disabilities are citizens first and their rights and responsibilities are equal to those of other citizens.

Government Roles

"The government needs to be courageous and realize that all things won't be resolved but that they must lead. Everyone is waiting for government to lead, and I want to know if there is the political will to change things. Everyone is frightened of change, but this doesn't give us the right to make decisions for our children. My son is willing to take risks, even if I'm not."

Historically, Alberta Family and Social Services has assumed a great deal of responsibility for services to people with mental disabilities. When institutional services were the primary care-providers, they were almost exclusively within the domain of Alberta Family and Social Services. There was a minimum of responsibility assumed by other government departments, and they tended to view the person with a mental disability as the responsibility of Alberta Family and Social Services.

In the 1970s, as community-based services expanded, more and more individuals with mental disabilities chose to live in the community and sought appropriate support services. At the same time, families kept young children with mental disabilities at home and began to turn to community-based services to meet the needs of those children. These services frequently were the responsibility of other government departments. Probably the most notable was Alberta Education and modifications to the school system.

Government Roles and the Future

In the future, as people with mental disabilities are integrated within the community, the role of Alberta Family and Social Services will diminish. At the same time, the role of other government departments will expand, as people with

mental disabilities will want services from the same government departments that provide services to other citizens. Alberta Family and Social Services may have a role helping other departments and service systems modify their services to make them more accessible. This must result in a re-allocation of resources.

> *"I am frustrated dealing with government departments that do not talk to each other or co-ordinate their programs."*

During this transition, government can be expected to play a leadership role in a variety of departments, for example, Alberta Education for primary and secondary school education, Alberta Advanced Education for post-secondary services, Alberta Career Development and Employment for training and employment programs, Alberta Health for community-based health services and hospital services, and Alberta Tansportation and Utilities for transportation services within the community. Alberta Family and Social Services will maintain responsibility for the support and services not available to the general public from other departments.

Based on the recommendations in this report and a further consultation process, government must provide leadership to determine what services will be supported by government, for whom they will be designed, and by what mechanisms they will be delivered and establish a policy commitment to the directions established. Policy setting must include establishing a legislative base and putting regulations in place, as well as less formal policy provisions that will be modified on a more frequent basis. Here, the government will be responsible for co-ordinating services and insuring that they are flexible and able to respond to individual choice. The services must be equitable and consistent so that all Albertans have the same access to the same services.

Another role of government will be to provide funds. This must include providing funds to individuals so that they can purchase their own support services and providing funds to agencies who are supportive to citizens with mental disabilities. Over time, the nature of the funding provided must change in response to the wishes and choices of people with mental disabilities. However, the fund mental responsibility for funding will remain with the government.

Finally, the government has a major responsibility to establish consultative mechanisms that will involve people with mental disabilities, their families, their personal support networks, agencies involved in providing services, and other

interested individuals. This consultation must be part of the monitoring process and will determine the impact of existing policies and funding approaches and will involve those affected in policy development and modification.

Recommendations

For Government:

1. That the Alberta government make a commitment to having services provided to people with disabilities by the same departments of government responsible for providing them to the general population.

2. That the Alberta government restructure any organizational units and resource allocations that result in services being provided to people with disabilities in a different manner than to the general population.

3. That all government departments review their mandates to ensure that people with disabilities are able to have access to and use all services contained within their mandates.

4. That all government departments immediately begin to review and formalize plans to ensure that individuals with disabilities are fully integrated into all systems.

For Alberta Family and Social Services:

1. That Alberta Family and Social Services develop a clear mandate for services to people with disabilities, delineating which services will be provided by this department and to which areas they will provide support for other departments.

2. That Alberta Family and Social Services provide training and assistance to help other service areas eliminate barriers to service access and adapt services as necessary to serve people with disabilities.

3. That Alberta Family and Social Services develop a policy to assist and support all individuals who wish to leave institutional settings, group homes or workshops that are not meeting their needs, to take advantage of more individualized and integrated options.

Legislation

"Legislated benefits are necessary so that individuals and their families are secure in the knowledge that it is their right to receive services throughout their lives."

Until now, services for people with mental disabilities have been provided under the Social Development Act at the direction of the Minister of Family and Social Services. Other pieces of legislation such as the Dependent Adults Act, the Child Welfare Act (HCS), and Income Security have a bearing on some of the services and support received, but there is **no specific piece of legislation** to ensure services for people with disabilities.

Services to people with disabilities have been dependent on a loose interpretation of whatever legislation currently exists. Services to people with disabilities have **not been secure** without specific legislation and, in times of restraint, it is the non-legislated services that suffer cutbacks. This **lack of security** has left people with disabilities in a **vulnerable** position, as they are **unsure of what services they should receive, how long they will receive them, or the quality of the services they can expect**. Without legislation, policy directions have been vague and there have been service gaps and inequalities. Some families may have held on to institutional services because they feel there is security in a facility that they do not find in the community.

The reliance on the good will of the government to provide services is no longer enough. Services to people with mental disabilities must be guaranteed in the same way as other services such as education or medical services are for the general population.

Legislation and the Future

With a move toward full integration and desegregation, we believe that it is imperative that security of support and services be established in Alberta. We believe that the future view of services to people with mental disabilities must be assisted and realized through the existence of specific legislation which establishes the right to services and provides security of those services. Such legislation needs to address equitable availability of services and support but cannot be restrictive or prescriptive as this will result in no individualization and choice.

Recommendations

For Alberta Family and Social Services:

1. That a task force composed of Alberta Family and Social Services consumers and families, service providers, and legislative planners be convened to address the development of a Person with Disabilities Act. The Premier's Council on the Status of Persons with Disabilities should be extensively involved in this process.

Appendix

The Public Consultation Process

In May of 1988, the Minister of Social Services, the Honourable Connie Osterman, established a Review of Services to the Mentally Handicapped. The purpose of the Review was to identify the values and philosophical base that will govern the evolution of services to individuals with mental handicaps in Alberta in the future. This philosophical base or conceptual framework must form a foundation for policy advice to the Minister in the future.

From the beginning, it was the intention of the Minister to have a review process that involved extensive consultation with the public. Every effort was made to develop as broad a range of options for input from the public at large as possible. In this regard, some interested individuals, groups, and agencies were relatively easy to identify, and their input could be solicited directly. On the other hand, some interested individuals and groups, particularly individuals with handicaps, their families, and other concerned individuals who are not aligned with an organization were difficult to identify and asking for direct input was not possible.

The approach adopted was to develop a list of questions (included below) that were quite broad, in order to focus discussion on the full range of services to people with mental handicaps. The intent of the questions was to have people step back from a particular service with which they were most familiar and reflect on a range of support or services that exist or ought to exist in society.

Everyone who could be identified as having a potential interest in the Review was sent a letter and the list of questions to stimulate their thinking. In addition, an advertisement explaining the function of the Review was placed in all Alberta daily and weekly papers on Wednesday, June 29, 1988. That advertisement indicated that public forums would be held to discuss preliminary input.

An information base was developed and circulated on November 23, 1988. Before finalizing the information base, approximately 109 submissions were received and included in that document. The information base reflected a wide range of views on the variety of topics and provided the public an opportunity to react to that range of views.

During the months of December, 1988, and January, 1989, public forums were held in seventeen locations throughout Alberta. At the public forums, individuals reacted to the information document, elaborated on the views or positions they had submitted, identified gaps in the information that had been provided to the Committee, and added written submissions for consideration by the Review Committee.

On completion of the public forums, the Review Committee considered all of the information provided in all of the ways and began to compile the final report.

Review of Services Questions

A. The Current Services

The current array of institutional and community based services were developed over a period of years and they were considered to be the most appropriate response at the time.

1. What are the strengths of the current array of institutional and community based services and how can future service development build on those strengths?

2. What aspects of the current array of institutional and community based services require improvement and what form of improvement is desirable?

3. Are there identifiable gaps in the array of institutional and community based services or is there an adequate range of support services?

4. What emphasis should be placed on the established approach of expanding community based services as an alternative to institutional options? What role should institutions such as Michener Centre play in the future?

B. Values/Philosophy

During the nineteen seventies and eighties, the primary value base which supported the development of the service system was "normalization." The use of this concept has been criticized as not being well defined or well understood, with the result it was used to support a wide variety of service approaches.

1. What value and philosophical underpinnings should drive the evolution of institutional and community based services as we approach the turn of the century?

2. What expectations should people with handicaps have about the opportunities available to them to participate in the ordinary life of society?

3. How can communities demonstrate a belief in the dignity and human worth of citizens with handicaps?

4. What philosophical view do you hold concerning the respective responsibility of government, individuals, families, and corporate citizens with respect to meeting the needs of individuals with handicaps?

C. The role of Social Services and other departments

A large number of provincial departments of government provide services to people with a handicap. Generally, there is an expectation that Social Services will provide a wide range of services to persons with mental handicaps if other departments are unable to do so.

1. What departments of government should be involved in providing services and how should their roles be defined? For example, should services to persons with a handicap be provided by or through the same provincial departments which provide similar services to other Albertans?

2. If the services which are accessed by the general population need to be adapted to accomodate persons with handicaps should the department responsible for the service be expected to make those adaptations without the involvement of Social Services.

3. If persons with handicaps are not able to access services designed for the general population and parallel services are required, which department

should be expected to develop those parallel services—the one responsible for the general service or Social Services?

4. For those services to persons with handicaps which are the responsibility of Social Services, what roles are appropriate for departmental staff, voluntary community agencies, the private sector, etc.?

5. For those services which are the responsibility of Social Services, what kind of policy provisions are needed for the future?

D. Resources

The adequacy of resources is a perpetual concern. Regardless of the amount of resources devoted to services to the mentally handicapped, there are three factors to be considered. First, the demand for service by individuals with a handicap. Second, the amount of resources available to meet the identified need. Finally, the manner in which available services are distributed amongst those who need them.

1. Is it preferable to have a service system which is resourced to provide a similar service to a group of people or one which focuses on individual need and individualized services?

2. Is it appropriate for government to provide financial support to individuals with a handicap and fund support services as well?

3. What role should families play in providing financial support or purchasing support services to children and adults with handicaps?

4. What role should charitable donations play in providing financial support or purchasing support services to children and adult with handicaps?

5. With particular reference to training and employment services what is an appropriate relationship with the private sector? For example, should employers play a role in providing training to adults with a handicap? Should voluntary agencies which offer training services be expected to cover some of their operating costs through production of goods or services to be sold in the marketplace?

E. Vocational Services

Vocational services to adults with mental handicaps have been provided primarily by Alberta Social Services and have largely been facility based according to the generally accepted approaches of the nineteen seventies and early eighties.

1. What departments of government should be involved in provision of vocational services and what should be their respective roles? For example, should services to persons with handicaps be provided by or through the same provincial departments which provide similar services to other adults?

2. What choice of vocational services should adults with handicaps be able to expect?

3. To what degree should persons with handicaps participate in decisions made with respect to delivery of their vocational services?

4. Are there new approaches to vocational services which hold promise of better meeting individual needs and which should be promoted?

5. What are the appropriate outcomes to be expected from vocational services? What should be the length of time service is provided to achieve the expected outcome?

6. What role should private sector employers be expected to play in the provision of vocational services? What types of supports are required by persons with handicaps and private sector employers to make such services viable?

7. To what degree should those delivering vocational services participate in the marketplace by selling services or products to the public? What should the relationship with the private sector be with respect to this activity?

8. To what degree, and in what manner, should those providing vocational services with government funds be accountable to the government?

F. Services to Support Community Living

In order to be integrated as fully as possible into community life, individuals with handicaps require a range of services which are necessary for all members of society. For example, medical and dental services, transportation services, cultural and recreational services, educational services, etc. In addition, they require time-limited or ongoing services which are related to their handicap such as residential supports, behavioral services, supports on the job and alternatives to employment.

1. What measures are required to ensure persons with handicaps have the same access to health care and other general services as other members of the community?

2. What directions should be taken in order to ensure that persons with handicaps are able to access services to maximize their independence?

3. What is the appropriate array of community based services to promote maximum independence and integration into the mainstream of community life?

4. What role is there for specialized or institutional services within the spectrum of community services?

5. Are there service delivery methods which will result in needs being met in a preferable manner and which would allow for more individuals to be served?

6. Are there new approaches to community living services which hold promise of better meeting individual needs and which should be promoted?

A citizen with a mental disability is:

– not a burden but an asset

– not an inmate but a neighbour

– not a strain on society but a contributing member

– not someone in need but someone who has much to give

– not strange and different but one of us

– not less than but the same as

– not someone to fear but someone to love

– not someone to be pitied but someone to share with

– not handicapped but a ***person***